Once a man, twice a child:
A phenomenological study of women of Jamaican heritage caring for a relative living with dementia

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I confirm that the intellectual content of this work is the result of my own efforts and no-one else. Except for express acknowledgements, references and or bibliographies cited, no part of this study has previously been presented in any form to the University or any other body for the purpose of assessment or publication.

Signature

Date 1 December 2020

Abstract

Little research has been done into the lived experience of caregivers of Jamaican heritage providing care for family members with dementia. Socio-cultural traditions in Jamaican families assign nurturing and caring roles to women, so that when a family member develops dementia it is females who take up the role.

The aim of the present study was to explore the lived experience of caregivers of Jamaican heritage living in both England and Jamaica. This study offers a unique and original contribution to our knowledge base as currently there is no published qualitative study that focuses on dementia caregiving in Jamaican families.

Using a phenomenological methodology, data were collected in England and Jamaica over a period of twelve months by semi-structured interviews with ten women of Jamaican heritage caring for a family member living with dementia. Participants were interviewed in Birmingham, England and Kingston, Jamaica. Findings revealed six themes relating to how women of Jamaican heritage experience and understand dementia caregiving. (1) strength and resilience; (2) a labour of love; (3) picking sense out of nonsense; (4) I'm not a carer - I'm family; (5) the role of the Church and (6) Jamaicans don't do that. The insight gained from these findings provided rich information about the participants' experiences of caregiving.

This study revealed that cultural values and upbringing within Jamaican families are important factors that support caregivers in dealing positively with the demands of caregiving. The main implications for practice from this study suggests is that the willingness and commitment of women of Jamaican heritage to provide long-term care within family units in order to maintain the dignity of their elders, as opposed to admitting them to care facilities, needs affirming and supporting. Also, there is a need for commissioners of services and support in England and Jamaica to recognise the importance of voluntary community groups and Black majority churches, when collating and disseminating information.

Acknowledgements

First and most importantly, this thesis is the product of the generous contributions of the women who took part in the study. Without their time and openness in talking to me and checking transcripts in addition to all the effort they put into providing care for their loved ones, there would be no thesis, and so I dedicate this to them.

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Glossary

African American

The term African American refers to a person of African ancestral origins who self identifies or is identified by others as African American. While the term African American has been used at least since the 1920s, it has been the preferred term in the US since the 1970s. As most African Americans in the US originated from sub-Saharan Africa, the term is not applied to Africans from northern African countries such as Morocco. Most African Americans are descendants of persons brought to the Americas as slaves between the 17th and 19th century (distant ancestry). Such persons differ from others who came from Africa or the Caribbean in the 20th and 21st centuries (recent ancestry), in terms of culture, language, migration history, and health. These differences are often ignored.

African Caribbean

The term African Caribbean is usually used in Europe and North American to refer to persons with ancestral origins who migrated via the Caribbean islands. The term African Caribbean/Afro-Caribbean when used in Europe and North America usually refers to people with African ancestral origins who migrated via the Caribbean islands. In the UK this term is used inconsistently. Some researchers use it to refer to people who are Black and of Caribbean descent, others to refer to people of either West African or Caribbean descent. The group African Caribbean is composed of people from a multitude of islands and the use of this term has been challenged, (Agyemang et al. 2005).

Black

Within this thesis Black with a capital ‘B’ is used in its broad political and inclusive sense refers to persons with African ancestral origins. While the term Black has a social and political significance, in health research is not that helpful (Agyemang et al. 2005) as it covers a wide range of ethnic and cultural backgrounds and conceals a remarkable heterogeneity of cultures among diverse populations.

Black Asian and Ethnic Minority (BAME)

BAME is a reductionist term used to categorise a diverse range of minority ethnic groups. It does not take account of the specific needs of each individual ethnic group who might not be included such as bi-racial people, white minorities or white communities with distinct lifestyles based on religion, ethnicity, language, age, gender, or sexual identity. The term minority also suggests marginality. It is argued that a new definition is required to capture the 'super-diversity' of ethnicity in the UK, (Vertovec 2007:1024). The parameters of this thesis can only acknowledge that until an improved language exists the researcher too falls within these semantic trappings.

Culture

Within this thesis, culture is the identification with the practice, thought and behaviours of a region, group or organisation – most notably associated with a geographical locality. Culture is the structural process that provides a framework for our behaviour (Regan 2014). It is thought to be flexible and amenable to change in response to new pressures, and uprooted communities become more conservative as a response to fear of losing their values (Parveen et al. 2011).

Diaspora

A Diaspora is a large group of people with a similar heritage or homeland who have since moved out to places across the world. The key difference between Diaspora and migration is that in Diaspora the people maintain strong ties to their homeland, their roots, and their origin.

Jamaican Heritage

According to The Global Jamaica Diaspora Council (2019) the term Jamaican or Jamaican heritage refers to persons who are so by birth; descent; acquisition by naturalisation; registration on the basis of marriage; being a commonwealth citizen; registration as a minor, or restoration (having renounced citizenship).

Chapter 1 Introduction

This chapter, outlines the layout of the thesis, my personal and professional motivations for undertaking this study, setting out background information, putting the study into context, and stating the aim and objectives

1.1 Organisation of the thesis

This thesis comprises five chapters.

Chapter 1 sets the scene by presenting the researcher profile, motivation for doing this study and the underpinning research aim. This is followed by background information regarding the Jamaican Diaspora situated outside of Jamaica to give a context for the study. Dementia is then defined within several models of care to illustrate how dementia is understood and the impact this has on how care is envisioned and delivered in health and social care support services. The prevalence and policy developments around dementia in Jamaica and the UK are outlined and the chapter closes by presenting the primary research aim and objectives and their importance and contribution to the existing body of knowledge regarding dementia caregiving within BAME communities.

Chapter 2 opens with a description of the process that was undertaken to provide a systematic approach to the integrative literature review of published qualitative studies of dementia caregiving across a range of BAME communities. A critical review of the twenty-three studies selected explores the issues and challenges of caregiving of people living with dementia in BAME communities. The chapter closes with a discussion of the gaps in the literature and rationale for this study.

Chapter 3 opens with my epistemological positioning and rationale for using a phenomenological approach. The methodology for the data collection, the framework used for the data analysis, as well as the process of data management and analysis of the participant interviews, ethical considerations and trustworthiness are discussed in detail. It is hoped that this will allow the reader to assess whether the claims and conclusions reached in the next chapter can be justified and supported by the data.

Chapter 4 presents the findings from the analysis of the participants' interviews and a discussion of the findings in the form of six themes presented individually; using a modified Long Data Excerpts Approach to allow the reader to make some assessment of trustworthiness and robustness through personally evaluating how the themes identified are grounded in the data.

Chapter 5 presents recommendations and conclusions by revisiting the research aim, reviewing the strengths and constraints of the study, its original contribution to knowledge, and as a Professional Doctorate, the implications for practice, suggestions for further research, and how the study findings might be disseminated. The chapter's closing section provides a reflection and a critical review of the research experience from the point of view of a novice researcher undertaking a study towards a Professional Doctorate.

1.2 Researcher Profile

Finlay and Gough (2003) state that the robustness of any qualitative research study requires that there is acknowledgement and presentation of the researcher's positioning within their study. Also as highlighted by Tuval-Mashiach (2017), by outlining my professional and personal interests, values, and experiences I hope to assist the reader to evaluate my perspective, so that the whole process of why I did the study, how I recruited participants and conducted the interviews, and my analysis and interpretation of the interview transcripts, are open and transparent to scrutiny.

This study, focussed on the lived experience of women of Jamaican heritage caring for a family member living with dementia, has been heavily influenced by my own experience as a woman of Jamaican heritage and as a caregiver for my mother who, with a history of high blood pressure and strokes, developed vascular dementia in 1997 and died in 2004. I had been a RN (Registered Nurse) for around 15 years when my mother became ill and, being the only nurse among my siblings, there was a presumption that I would know all there was to know about dementia, which I did not. Somehow, as a family we muddled through what was a bewildering, exhausting and at the time a very painful journey of discovery for us, with all the attendant emotions of loss, anger, love and loyalty. The title of this thesis, 'once a man, twice a child', is a popular saying used by Jamaicans, but only as a mother, caring for my own mother, did I truly grasp the concepts of care, support, love and nurturing encapsulated in this simple phrase.

Over 50 per cent (of approximately 300,000) Caribbean migrants who came to England between 1950 and 1970 (Byron 1994, Chamberlain 2006), were from Jamaica. My formative years growing up were spent in Birmingham in the 1960s and 1970s within a lively and vibrant community surrounded by many other families newly settled in England, who, as noted by Goldthorne (2002) and Chamberlain (2006), were in England seeking a better life for themselves and their families.

My parents were two of the most talented, gifted, and hardworking people I knew. My mother came from a long line of schoolteachers and was also a seamstress who could sew and crochet almost anything (without a pattern), which meant that my sisters and I were always very stylishly turned out. My father was a Minister of Religion and also ran a very successful tailoring business in Kingston, Jamaica, which he continued in England. Growing up, I, along with many of my contemporaries, had little reference to older Black people. Our grandparents lived in Jamaica and almost everyone we knew was around the same age, or slightly younger than our parents who were in their mid-30s when they arrived in England. My parents, like so many of those early migrants, never intended to grow old in England. As reported by Byron (1994, 1999), and resonant anecdotally, most Jamaicans on their arrival in the early 1960s were adamant that they would only be staying for five years. Many elders who retired during the late 1980s and early 1990s did return to Jamaica, and I can recall frequent 'send-off' services at church. In 1986, my father died in England, so my parents did not return home as anticipated. What has happened since the 1990s is that this group of elders, because of their relative youth when they arrived in England, has seen a great swell of people all ageing at the same time.

1.3 Why I did this study

The incidence of dementia, (which is defined and outlined in detail later in this chapter), particularly vascular dementia, is increasing rapidly in England, and more rapidly within the ageing Black Jamaican community compared with the white British-born population, due mainly to the higher incidence of hypertension [high blood pressure] and diabetes (Adelman et al. 2009). Currently, (in the UK), around two-thirds of all older people with dementia are supported and cared for by family members (National Audit Office 2017) and this is especially true of Caribbean families who, according to the Department of Health (DH) (2015), are less likely to access specialist health and social care services. Although it is reported, (Adelman 2009), that General Practitioners are at least as likely to recognise and document a diagnosis of dementia in African Caribbean people as in the white British population, they are less likely to refer them for specialist assessment. This finding is supported by Cooper et al. (2009) and Truswell et al. (2016), who found that BAME communities had lower presentation at specialist services than the indigenous population, and even if they were referred, they face formidable barriers in accessing the few services available. The Department of Health (DH) (2015) reported that 80% of BAME families living with dementia may still not be receiving any service that could benefit them. Daker-White et al. (2002), Mukadam et al. (2011) Moriarty et al. (2011), Giebel et al. (2014) and Parveen et al. (2017) highlight a variety of reasons for this such as language barriers, different attitudes to ageing, dementia not being perceived as an illness, negative experiences of mental health services in the past, and the reaction of professionals when BAME individuals present to them. Over several years suggestions have been put forward (Keating & McCulloch 2002, Campbell et al. 2004, Bhattacharyya & Benbow 2013, Blakey et al. 2016, Truswell et

al. 2016) to improve this situation, such as increasing professional specialised knowledge of cultural diversity and culturally informed support to address cultural barriers. But, because dementia care (in England) cuts across Mental Health services, Older Adults services, Primary care, Social care, Acute care, Care Homes, Independent, Charity, and Voluntary sectors, providing joined-up, consistent, and culturally informed information and services, the National Audit Office (2017) advises that existing services need to be adapted to meet the growing needs of BAME groups, or new services need to be developed. There have been small pockets of innovative development of dementia support targeting BAME communities emerging across the country such as The Pepper Pot Centre[1], the Dementia Alliance for Culture and Ethnicity[2], Culture DementiaUK[3], Nubian Life[4], and Pearl Support Network[5]. The work of Culture DementiaUK probably provides one of the best examples of these BAME initiatives. Initially starting out in 1998 as a small local group of volunteers known as Friends of African/Caribbean Carers and Sufferers of Dementia (FACCSD), this service grew out of the founders' experiences of dementia within their own Jamaican families in the UK. The charity subsequently changed its name to Culture DementiaUK and is currently growing into a national organisation providing information to many different ethnic communities and forming partnerships with a variety of other voluntary and public sector organisations. While these are great initiatives for providing information and support to caregivers, on their own they are insufficient to address the major issues highlighted above.

[1] https://www.pepperpotcentre.org.uk/about-us

[2] https://www.demace.com/

[3] https://www.culturedementiauk.org/

[4] https://www.nubianlife.org.uk/

[5] https://pearlsupportnetwork.org.uk/

When the UK government launched its first National Dementia Strategy for England and Wales in 2009 (Department of Health (DH) 2009), one of the most striking phrases was a comment in the Foreword by Alan Johnson MP, the then Secretary for Health, where he stated *"all we need to do is ensure that the public and professionals have the full facts*". Interesting. Kuhn (1970:38) sums up my thoughts on reading this:

> *…a problem must be characterised by more than an assured solution. There must also be rules that limit both the nature of acceptable solutions and the steps by which they are obtained. To solve a jigsaw puzzle is not, for example, 'merely to make a picture'. Even a child could do that by scattering selected pieces, as abstract shapes, upon some neutral ground. The picture produced might be far better and would certainly be more original than the one from which the puzzle was made, nevertheless such a picture would not be the solution. To achieve that, all the pieces must be used, their plain sides must be turned down, and they must be interlocked without forcing until no holes remain.*

So, what did the UK government actually know about dementia care in the Jamaican community living in England that was going to enable them to create a picture that would be the solution for supporting family caregivers? How would they ensure that they would be able to locate any missing pieces, or would they ignoring Kuhn's premise, simply create a picture without them? Was it not reasonable to expect that as the Prime Minister had clearly invested a great deal of time and resources in the launch of this strategy, there must have been some mechanism for ensuring they had all 'the facts' before broadcasting the solution? But, with 40 years experience as an RN (Registered Nurse) working within health and social care organisations, I have gained a great deal of insight regarding strategies, for example, the care of older persons under the Mental Health Act 1983, and the Community Care Act 1990,

that have been implemented in a way no one would have, or could have, ever envisaged.

At its launch, the aim of the National Dementia Strategy (DH 2009) was to ensure that significant improvements would begin to be made to dementia services in the UK across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The strategy identified 17 key objectives which, when (if) implemented, would result in significant improvements in the quality of services provided to people with dementia and promote a greater understanding of the causes and consequences of dementia. This strategy was to be the catalyst for a change in the way that people with dementia were viewed and cared for in England. The then Prime Minister, David Cameron, gave new impetus to the Dementia Strategy with the Prime Minister's Challenge on Dementia (DH 2012:2), which stated "*we must ensure that every person gets the treatment and support which meets their needs and their life"*, and the key aims were refocused as: improved diagnosis, better support for carers, dementia-friendly communities, and improved research. Stemming from my time as a family caregiver I had become more active in engaging with debates and discussions around developing local implementation plans, and around this time it was noted that concerns were being mooted by policy-makers (Right Care, Right Here 2012) that changes in BAME family structures might mean fewer family carers willing or able to look after family members at home leading to an increased need for nursing home care. It had already been reported that people from BAME communities were less likely to enter long-term care facilities, (Cooper et al. 2009, Knight & Sayegh 2010) so where was this coming from? Who was positing these ideas? Prior to data collection, in meetings with the National Clinical Director for Dementia at the Department of Health (Burns 2012) and an All Parliamentary

Group on Dementia in London (APPG 2013), I raised the point several times that there was a huge difference between being *represented* and being *heard*.

During initial reading, I had come across Whitman (2010), an insightful collection of stories from family caregivers across a range of communities about their experiences of caring for a family member with dementia. These stories presented the lived reality of a diverse range of families in a profound way. One of the observations that struck me most while reading these stories was that, in England, the welfare state from the National Assistance Act (1948) appeared to be so firmly embedded in British culture that for many there was an expectation, if not a belief in a fundamental right, that the government should provide care and facilities to look after elderly family members; while in Jamaica, where approximately 300 000 persons (roughly 10% of the population) are over the age of 65, apart from certain facilities for the 'indigent poor' there are few state institutional care facilities for the elderly with long-term conditions. In Jamaica there is church and Non-Governmental Organisation (NGO) funded provision, but there is no expectation that their limited capacity could ever provide comprehensive or coordinated care. I also discovered that there remains still, enshrined in Jamaican law as part of the Maintenance Act (2005) Part V 10 [1], (Appendix 1:181) (An act to centre obligations on spouses to maintain each other, on parents to maintain their children and on persons to maintain their parents and grandparents), the obligation of families to support their elderly relatives. So, in Jamaica there appear to be clear expectations regarding family responsibility, and although Jamaica faces similar challenges regarding a population living longer in old age, 80 per cent of the caregiving for elders is managed by family members (Eldemire-Shearer 2008, 2017). During a fact finding visit to Jamaica regarding the care of elderly persons with dementia, I arranged a meeting at the

University of the West Indies with Professor Eldemire-Shearer who is a senior advisor to the Jamaican government regarding the care of the island's elderly (Eldemire-Shearer 2012). it was stressed and reiterated that institutional care was not a model that anyone wanted to see introduced in Jamaica. I wondered then, if the impact of the legislation in Jamaica was hard-wired into the psyche of Jamaicans which was why there was so little engagement with services or policymakers in England. The main impetus to undertake this study was therefore both personal and professional.

Adelman et al. (2011) noted that the prevalence of vascular dementia in the African Caribbean population was greater than that in the white British population, and the age of onset was younger than in the white population since, African Caribbean people were more likely to experience health complications such as high blood pressure and diabetes, which are predisposing factors for vascular dementia. In addition, there was evidence (Lawrence et al. 2008, Adelman et al. 2009b and DH 2009 Parveen et al. 2017) that around two-thirds of older people with dementia were being supported by family members. Limited experience of caring for elders, and changes in family structures, suggested that fewer Jamaican families in England might be willing or able to look after family members with dementia at home. Pondering on the fact that Jamaica has a national policy for care of its elderly yet to date has not developed residential care or nursing home facilities on any significant scale, I wondered if this could cast some light on the missing voices from the Jamaican community in England in policy development. Or, was there something in the notion that, in the natural order of things, in a developed country such as England in the 21st century the state welfare system should and would provide care

for its elderly, and that as British Jamaicans we would simply assimilate this norm, thus creating the predicted increase in the requirement for long-term care facilities.

Given that family structures and roles differ within BAME groups, my original contribution to knowledge in this area is to highlight the lived experience of Jamaican caregivers whom very little is known. In conducting this study in England and Jamaica, a cultural focus to the research would be addressed, as to date no qualitative studies around dementia caregiving have been done in Jamaica and the majority of participants in research around dementia and BAME family caregivers in the UK has focused on South Asian populations (Jutlla 2011, Mukadam et al. 2011, Parveen et al. 2013, 2017). As a woman of Jamaican heritage born in England, I wanted to understand the lived experience, realities and collection of stories from family caregivers in England and Jamaica providing care for a family member living with dementia. It was important to consider how that understanding might provide some answers to developing a holistic approach for caregivers from a BAME background in a profound way. The research question underpinning this study emerged as “What is the lived experience of family caregivers of Jamaican heritage caring for a relative living with dementia?

1.4 Research aims and objectives

The aim of this study was to explore the lived experience of dementia caregiving by caregivers of Jamaican heritage living in England and Jamaica.

To achieve this, the following objectives were identified:

1. To explore the experiences of family caregivers in England and Jamaica
2. To explore influences that impact on family caregivers' ability to provide care and cope with their role
3. To explore the expectations of family caregivers for long term care provision for their elders.

1.5 Background Information to the study

1.5.1 The Jamaican Diaspora

The African Caribbean community has a long-standing relationship with the UK, playing a central role in the development of the economic power of the British Empire as a result of chattel slavery of Africans transported to the Caribbean, (Fryer 1984, James & Harris 1993, Beckles & Shepherd 2007). While the presence of people of African heritage in the UK is longstanding through this association with the trade in slaves, with the abolition of slavery and the subsequent colonial status of the Caribbean islands, the flow of migration from the Caribbean to the UK has persisted. This has been fuelled by push factors, such as the limited economic opportunities in the islands as the colonial power drained resources and capital from the economies and pull factors such as labour shortages in the UK (Peach 2005).

During WWII many thousands of people from Jamaica, which was at the time still a British colony, volunteered for the armed forces and to work in munitions factories

(Olusoga 2014). Their return home after the war led to disillusion with stagnant or declining economies which, coupled with the labour shortages they had witnessed in England, led many to make a second voyage to England, this time in search of civilian employment, (Byron 1994). Their status as British citizens in the colonies meant that they had free entry to, and right of abode in England. The first group of 492[6] people from the Caribbean arrived aboard the SS Empire Windrush in 1948 and were swiftly followed by relatives and friends in what was described at the time by MacDonald and MacDonald (1964) as a classic case of chain migration. In addition to labour migrants, many Jamaicans, as reported by Goldthorne (2002), Thomas-Hope (2004), and Chamberlain (2006) came to England to better themselves, either economically or by furthering their education. Studies within these new migrant communities (Byron 1994, Byron and Condon 1996, Byron 1999) have supported anecdotal memories and many conversations of the view that the vast majority of these migrants intended to stay for only five years, but fewer than expected actually returned to the island (White 2006), and the majority remained in England.

In 1951 the Caribbean-born population in England and Wales was 17 218, rising to a peak of 304 070 in 1971 then gradually decreasing due to stricter immigration laws with the introduction of the Commonwealth Immigrants Act (1962), and as reported by Peach (2005) a slow return for some back to the Caribbean. The sharpest decline to date in the number of Jamaican migrants in England occurred during the 1990s due to large numbers migrating back home on reaching retirement. According to Byron (1999), migration of Jamaicans to England helped to integrate them into a

[6] Although the popular figure of those arriving is quoted as 492, the official passenger list was 1027 of which 802 listed their country of residence as the West Indies. They included 539 Jamaicans, 139 Bermudans, 73 Trinidadians, 44 from British Guyana, and the rest from Mexico, South America and the other West Indian islands. There were 964 males, 257 females, 50 boys and 36 girls. (Rogers & Ahmed 2018)

global socio-economic network. For Jamaicans, as for many migratory groups, these movements to other countries have linked the place of their birth into a wide social field, which in many senses defies national boundaries. Links have been maintained and constantly cemented, as Jamaicans have created strong transnational communities (Dovelyn and Newland 2011). So much so that the food, culture, and language of Jamaica has been transposed onto the streets of Birmingham, London, Toronto, and New York, and many Jamaicans do not now see a permanent return home as the ideal retirement, but rather see being in touch, (Thomas-Hope 1999, 2006, Ying 2014), as much more important.

There are a variety of terms used across the literature to refer to transnational communities, some of these terms include but are not limited to ‘absent migrants’, ‘expatriates’, ‘nationals abroad’ or ‘diaspora’. Vertovec (1997 2007), and Dovelyn and Newland (2011) concur in the definition that diasporas emerge when groups that migrate from one location to at least two others develop a collective memory and vision of their homeland and they seek to improve or maintain transnational economic, cultural and emotional exchanges. The use of the term diaspora in this study is best defined by Mullings (2010) who describes it as the social space created by populations of Jamaicans (either by birth or heritage) who have lived periods of their lives away from Jamaica, but whose identities connect with the people and the cultural practices of the island. Members often experience a sense of alienation or non-acceptance as full citizens in their host countries and this contributes to their desire to maintain ongoing ties with their home countries. While once defined by their location away from their home country, diasporas today include not only second generations who have never migrated, but also migrants who take up residence in their home country after having lived abroad (Mullings 2010). Transport and

communication systems have meant that physical location is no longer the primary defining feature of a diaspora, but rather the exchange of collective memories, ties and investments in the welfare of their homeland. Many returning residents, for example, engage in circular patterns of migration, maintaining social, business, professional and even residential ties in the host countries even after they return home.

The Jamaican diaspora as summarised in Table 1:1 is concentrated primarily in the US, Canada, and the UK. Ying (2014) estimates 1 700 000 Jamaican-born people as resident in the US, 300 000 in Canada, and 800 000 in the UK. The size of the Jamaican diaspora is, however, likely to be much larger because these statistics only include those who are Jamaican born, and exclude all persons of Jamaican heritage.

US	UK	Canada	Other Locations	Total
1 700 000	800 000	300 000	200 000	3 000 000

Table 1:1 Summary and size of the geographical distribution of the Jamaican Diaspora (Source: Ying (2014) Jamaica Diaspora Institute, Jamaica)

According to Ying (2014) Jamaicans in the United States, who live mainly in New York and Florida, are generally well educated and more likely to participate in the labour force than the native-born population. Data from the US Census Bureau (2008), which are the most current statistics available, show that about half of the Jamaican-born population aged 25 and older had at least some college or an associate degree in 2008, of which a larger share of Jamaican-born women held a Bachelor's degree (24%) than Jamaican-born men (19%). Thirty-seven per cent of Jamaican Americans aged 16 and older were reported as working in education,

health or social care. The Canadian census (2006) also indicated that Jamaicans living in Canada are also likely to be educated with 12.5% of Canadians of Jamaican origin obtained a university degree compared with 18% of all Canadian adults. Also, Jamaican Canadians were more likely than those in the rest of the population to have completed a community college programme and were also more likely to be employed than other Canadians. Again, information from the Canadian Census (2006), showed that 66% of Jamaican Canadians aged 18 and older were working, compared with just 62% of Canadian adults overall. Of those employed, around 25% were in sales and service occupations, while 20% were in business, financial or administrative occupations. A significant proportion of Jamaican Canadians were also employed in health-related occupations. In 2006, about 9% of Jamaican Canadian workers were employed in this field, compared with just over 5% of workers in the overall population. The majority of Jamaican Canadians in 2006 were bilingual in English and French.

In the UK, according to official census data (ONS 2011), two-thirds of the total Jamaican-born population hold British citizenship. However, there is also evidence to suggest that some Jamaican migrants live in the UK without proper documentation for settled status, although it is very difficult to accurately estimate such numbers. The majority of the Jamaican British population live in London, although there are considerable Jamaican communities in other parts of the country, particularly in the Midlands and the Southwest. Among foreign-born workers in the UK, Jamaica is one of three origin countries where employment rates for women are higher than those for men. In 2011, (ONS 2013) 73.8% of Jamaican British women were employed in the United Kingdom, compared with 66.1% of Jamaican British men. As a result of tighter immigration controls, the official flow of Jamaican migrants to the US,

Canada, and the UK has been falling steadily over the past few decades, with the number of those emigrating to the US declining by around a third between the 1970s and 2006 as shown in Table 1:2

Decade	Total number of migrants	United States	Canada	United Kingdom
1970s	327 779	256 984	56 964	13 831
1980s	239 207	201 177	33 973	4 057
1990s	212 892	170 291	39 443	3 158
2000-2006	135 493	117 205	15 374	2 914
Total	915 371	745 657	145 754	23 960
% of Total	100	82.4	15	2.6

Source: Thomas-Hope 2004 (updated to 2006). Compiled from data in the Economic and Social Survey, the Planning Institute of Jamaica, volumes for years 1970-2008.

Table 1:2 Official Flow Data on Primary Destinations of Jamaican Emigrants by Decade, 1970s to 2000s

Jamaicans across the Diaspora have a general cultural familiarity with caring for elders, framed by historical experience in Jamaica where extended family members were close by and recruiting additional support was easy through culturally shared expectations in the community. However, the Diaspora experience means it is not uncommon for contemporary multigenerational Jamaican families to be dispersed across the UK, US, Canada and Jamaica.

1.5.2 Models of health care in dementia management

Although dementia is often conceptualised socially, culturally, and professionally as a disease of old age, and the risk of developing dementia increases with age which creates a sense of fear in ageing populations, it is not part of the normal ageing process (Hampson and Morris 2017). The term dementia describes symptoms that occur when the brain is affected by irreversible chemical and neurological changes that result in progressive functional and behavioural deterioration (Morris and Morris 2010). Symptoms of dementia include, loss of memory, mood changes, and communication difficulties. In the late stages of dementia, persons affected have increasing challenges carrying out everyday tasks and become increasingly dependent on others for support in activities of daily living.

There are several conditions which cause dementia. Alzheimer's Disease is the most common, but others include;

- Vascular dementia;
- Dementia with Lewy bodies;
- Fronto-temporal dementia (including Pick's disease);
- Progressive supranuclear palsy;
- Korsakoff's syndrome
- Binswanger's disease
- HIV and AIDS
- Multiple sclerosis
- Motor neurone disease
- Parkinson's disease
- Huntington's disease

Each person's experience with dementia is unique. How fast a dementia progresses depends on the individual, their environment, and the underlying pathology, but dementia is a chronic illness which means it gets worse over time, and at present, there is no cure or universally accepted, effective treatments (Hurtley 2010). From

the point of diagnosis, a person with dementia can currently expect to live an average of around three to nine years (Helzner et al. 2008, Truswell 2013).

Some illnesses and conditions follow a predictable path to which a care pathway and care model can be effectively applied for example, an older person experiencing a myocardial infarction would have all the anticipated treatments and interventions mapped out to achieve agreed goals and health outcomes, For dementia, however, there is no one size fits all care pathway or model of care that can be applied in this way because the symptoms associated with dementia can be attributed to so many different causes, making the need for personal centred dementia care extremely important (Dewing 2008). The purpose of any model of care is to improve health and quality of life. Therefore, any dementia care model must take a holistic and person-centred approach to caring for persons with this condition. Personhood is the recognition and value of all people (regardless of race, gender, disability, age or cognitive ability, and is a status that one individual bestows on another. (Kitwood 1997). The concept of person is one of the foundations for models of health care (Dewing 2008). In upholding personhood many factors are involved, including culture. It has been argued, (Kitwood 1997), that the challenge is not dementia itself; rather the real challenge is 'our' individual, professional, and societal inability to accommodate personhood in health care. Therefore, there is a danger of creating/maintaining a 'them' and 'us' dialectic tension that has become reinforced over the years by the socially constructed and devalued status of people with dementia. Dementia care requires recognition and understanding of the person (Dewing 2008). Personhood can be supported positively or negatively by the model of care employed, and unfortunately, negative attitudes towards dementia may diminish personhood (Kitwood 1997, Dewing 2008). However, developing a care

pathway in dementia is not straightforward, as health systems and health and care facilities in England and Jamaica determine their own service criteria, and referral routes to specialist care vary considerably. Person-centred care and professional discretion, the guiding principles of good quality dementia care, complicate the suggestion of a care pathway as a unified approach. In particular, individuals are likely to prefer different approaches to how they are assessed, referred, and diagnosed, (Samsi et al. 2014), and they often have other long-term conditions, such as hypertension or diabetes which impact on what they do and think about dementia symptoms.

An outline of the models of care most often used in dementia care are outlined below to demonstrate the points raised above.

1.5.2.1 Biomedical Model of health care in dementia management

Conventional ways of defining and describing dementia draw largely on medical and clinical language and arguably problematises it in terms of ageing demographics. The Department of Health, in England (DH 2015) defines dementia within a biomedical model as a syndrome which may be caused by a number of diseases where there is progressive decline to multiple areas of brain functioning, such as memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, and can occur at any stage of the illness. In Jamaica, the Ministry of Health also defines dementia within a biomedical model, as a clinical syndrome of progressive impairment of memory and intellectual function, language

and motor skills, resulting in significant impairment of cognition, function and behaviour as well as an increase in care needs (Eldermire-Shearer 2017).

As outlined above dementia is not a disease in itself. The use of the term Alzheimer's Disease as a generic label dementia came into common usage after Dr Alois Alzheimer published the first clinical case of dementia in 1907 by identifying a cluster of symptoms, and it was Dr Emil Kraeplin in 1910 who first classified dementia as a 'disease'. Successive historical convergences have formed the current UK definition of dementia in the International Classification of Diseases (ICD-10) (WHO *2016: F00-F03)* as:

> …. *a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.*

Knapp et al. (2007) document a Cognitive Function and Aging Study by the Neuropathology Groups of the Medical Research Council done in 2001 which indicated that the most widespread form of dementia when studied after death represented a mix of conditions, for example a combination of Alzheimer's disease, vascular dementia, or disorders linking viral or toxic/metabolic issues or Huntington's disease. This means that the clear-cut subtypes outlined at Appendix 1:176-180 do not actually exist. It has been argued (Wyatt and Midkeff 2006, Summerfield 2008), that the evidence supporting the theory of biological aetiology in dementia or affirming genetic predispostions is not conclusive, and there is no intervention or

medical ‘cure’ for dementia to justify the dominance of the biomedical model. It is important to note that it has also been asserted by Fernando (2008) that the biomedical model’s evidence base is loaded with political, moral, social and cultural contexts since it is based on assumptions embedded in white European and American positivist cultures. The dominance of this model is linked to the imperialist principles of such cultures which deem their specific values and standards as authoritative while imposing a sense of compliance from other cultures, implied when as argued by Fernando (2008) they override other models of health. Criticisms of the biomedical model have existed for some time, Kitwood (1997) argued it was deficits-focused, scientifically flawed and therapeutically nihilistic. He suggested that families supporting a person with dementia accepted the biomedical model because often it is presented as the only explanation for dementia, despite evidence (Alzheimer’s Society 2015) that scientists do not really fully understand dementia which is often the result of a complex interaction of genes, lifestyle factors and environmental influences. Wide-scale acceptance of the biomedical model has also impacted on how care and caregiving relationships have been constructed, as research and practice continue to focus on the person’s condition as the problem, and decisions made by professionals and others who claim to know what is best.

1.5.2.2 Social Model of health care in dementia management

It has been argued (Means et al. 2003, Gillard et al. 2005, Williamson 2015) that dementia should be viewed more within a social model, drawn from the social model of disability. At the core of the social model of disability is a human rights perspective. However, as debated by Donnelly (2014) and Williamson (2015) the human rights lens has not been widely applied to the lived experience, the policy response or the services that are provided for people with dementia. People with

dementia frequently reside in the medical model, with others, particularly clinicians, who often make decisions on behalf of the individual, prescribe treatment regimens (often pharmacologically focused) and retain (sometimes unintentionally) the power in the relationship. The social model contests the way in which policy is developed and services delivered and highlights that although a person with a diagnosis of dementia may exhibit changes in their behaviour and have difficulties with some cognitive functions, it is how they are marginalised and treated by others which results in the greater impact to their quality of life and wellbeing.

1.5.2.3 Psychosocial Model of health care in dementia management

This model allows for an integration of the biological, psychological and social aspects of dementia. Milne and Chryssanthopoulou (2005) suggest exploring the extent to which Western models of illness fuse with ethnic models where the mind, body and social circumstances are perceived as inseparable so dementia may be understood differently, an argument also espoused by Fernando (2002).

As summed up by Marks et al. (2005), the psychosocial model's view of dementia requires practitioners to attempt to understand people with dementia and how they act in the context of their social circumstances and cultural background. Instead of seeing behaviours merely as symptoms of a disease, this model sees behaviours as attempts to communicate, and Botsford et al. (2011) highlight that a person's cultural background is an aspect of their identity that is extremely important when seeking to engage that person or communicate with them or their family, because the way that dementia is conceptualised is very much influenced by the cultural lens through which it is viewed. For example, in Mahoney et al. (2005) comparing African American and Hispanic caregivers' perceptions and experiences, it is reported that while both groups were alike in attributing symptoms to old age, African Americans

referred to an ‘old timers disease’ whereas Hispanics used the phrase ‘el loca’ (referring to craziness). Lawrence et al. (2010) found that Black Caribbean people in England with dementia feared being viewed as ‘mad’, and generally within this community anything to do with mental health is viewed negatively. This means that there is often a strong desire to portray an image of wellbeing to everyone outside the immediate family, and to isolate and keep private any illness, as reported by Moorley (2012) in relation to the experiences of African Caribbean women after a stroke. In contrast, a US study by Dilworth-Anderson and Gibson (2002) within the African American community found little or no such concerns associated with dementia. Instead dementia was conceptualised as an expected reaction to worry, high blood pressure, and stress. Elders were expected to be vulnerable to mental and physical stresses and illness, as a result of exposure to hardship and oppressive conditions. This means there was a lack of perceived concern about needing help as they got older, though there was an expectation that care would be provided by the family rather than from outside health or social care services. A study by Cox (2007) also showed both groups to be similar in terms of patterns of using family or professional support, with the preference being for family support. Dilworth-Anderson (2002) showed similar findings for the South Asian, and Chinese communities in England, but no similar evidence exists for the African-Caribbean community. Kleinman (2000) and Cox (2007) suggest a fundamental anthropological idea that culture strongly affects subjective understanding of health illness, and care, and that culture and values influence the way symptoms of dementia such as wandering, confusion or forgetfulness are perceived. Kleinman (2000) argues vehemently against the rationale for assuming that the meaning of dementia can be translated across cultures in a purely medicalised international

classification. Therefore the continued promotion by the World Health Organisation (WH0 2016) of the adoption of the ICD-10 definition of dementia cited earlier, not only in the UK but globally, appears to reflect cultural insensitivity and apparent disregard for the idea that such globalising of dementia as a biomedical syndrome invalidates diverse cultural beliefs, and assumes imperialist superior authority. Although there has been work (Rait et al. 2000), on addressing culture-specific versions of diagnostic screening tools such as the MMSE[7] this global definition could impede further development. More worryingly, according to Watters (2010), this could lead to pharmaceutical companies contributing to the '*health promotion'* of cultural difference in order to gain evidence for cultural understanding of mental illness and paradoxically shifting these closer to Western diagnoses. In doing so, they may be influencing traditional understandings to fit biomedical models (which are already considered universal) in order to profit from them.

The 2020 vision highlighted in the National Dementia Strategy (DH 2015) is fuelled by a desire to be person centred in its approach. The psychosocial approach to dementia reminds us that a person with dementia is no less a person than anyone else and efforts should be made to maintain and improve quality of life by respecting and preserving the individual's personhood.

[7] The Mini Mental State Examination (MMSE) is the most commonly used test for complaints of problems with memory or other mental abilities.

1.5.3 Prevalence and policy developments

1.5.3.1 Jamaica

There is evidence that the prevalence of dementia is increasing in Jamaica (Prince et al. 2015, Eldermire-Shearer 2017). The 2015 estimated worldwide prevalence of dementia was 5 - 7% but the Caribbean had a higher prevalence of 6.5% – 8.5% while Africa, for example, was lower at 2.4% (Prince et al. 2015). For the population aged 60 years and over, Alzheimer's Disease International (Prince et al. 2015) estimated the 2015 crude prevalence in Jamaica at 6.5%, and that relative to 2015 proportionate increases of 60% and 183% would be realised by 2030 and 2050 respectively. Consequently, among the Jamaican elderly of approximately 300 000, (Jamaica Population Census 2011) the current estimated 19 000 people with dementia will increase to 31 000 in 2030 and 55 000 in 2050.

In Jamaica dementia care and support are associated with high social and economic cost both to the country and the individual. Dementia is the largest single reason for the need for care by older people (ADI 2017). Apart from certain facilities for the 'indigent poor' there are few state institutional care facilities for the elderly with long-term conditions. There is church and Non-Government Organisations (NGO) funded provision, but there is no expectation that their limited capacity could ever provide comprehensive or coordinated care, and at present there are no policy discussions or plans to develop any such facilities. Most notably however there remains, enshrined in Jamaican law as part of the Maintenance Act (2005) Part V 10 [1], the obligation of families to support their elderly relatives.

1.5.3.2 England

Until recently it was generally accepted that rates of dementia were lower among BAME communities in England due to their younger age profile (Seabrooke and Milne 2009). However, as the age profile of BAME migrants changes, and the number of those over the age of 65 years increases (ONS 2013), the previous estimate by Knapp et al. (2007) of 11 392 people with dementia from BAME communities by 2015 was seen to have more than doubled when the Centre for Policy on Aging and the Runnymede Trust (2013) applied established dementia prevalence rates to census data, with a revised estimate of nearly 25 000 people with dementia from BAME communities and this number is expected to grow to nearly 50 000 by 2025, and 172 000 by 2050. This will be nearly a seven-fold increase in forty years compared with the two-fold increase in the numbers of people with dementia across the whole population in the same period. As age is a significant risk factor for dementia, the prevalence in BAME communities is increasing, and in terms of differential rates, evidence from studies such as Adelman et al. (2011) that African Caribbean persons are at increased risk of vascular dementia due to higher incidence of hypertension and diabetes impacts further on these figures. Lievesley (2013), further supports the notion of these figures in updating his previous work on the UK BAME ageing population, when he points out that the 2011 census shows that of those identified as Black African Caribbean aged over 65 and likely to be living with dementia, the figure may well have been considerably underestimated as it assumed that the Black African Caribbean population had the same prevalence of dementia as the indigenous white population. In fact as the evidence (Livingston et al. 2001, Lawrence & Banerjee et al. 2010, Adelman et al. 2011,) is increasingly suggesting that the prevalence rate is higher for the Black African Caribbean population with greater risk factors for vascular

dementia, due to hypertension and diabetes (Adelman et al. 2009, 2011, Moriarty 2011) current policy planning for care of older persons in the UK, begins to highlight some of the challenges mooted back in 2012 regarding an increased need for long-term care facilities. (Right Care Right Now 2012).

The Alzheimer's Society (2015) reports that the cost to the government of residential care for people with dementia would have to more than double from £3.8bn in 2015 to 8.5bn by 2030, to accommodate this increasing numbers of persons, which is potentially a real anxiety for policy-makers. With such huge costs projected, the call for reform of care in the UK, amid the mounting pressures of increasingly savage funding cuts and an ageing population that could see a rise in the number of people with dementia requiring care home provision jump from 312 695 (DH 2015) to just under 500 000 by 2030, has become ever more pressing and urgent. These projections mean that an estimated 175 000 extra care-home places might need to be created in the next ten years to make up the shortfall. The Department of Health (DH 2015) insists that the government is doing more than ever before to transform care, awareness, and research into dementia, and in part this is evidenced by the 2020 vision document (DH 2015). But the recognition that people from different cultural backgrounds may have particular care needs and challenges remains under-addressed even though first articulated in the National Health Service and Community Care Act (1990), which established a framework for major changes in the delivery of health and social care. The Community Care Act (1990) required the statutory sector to engage with the independent sector and work in partnership with care recipients and caregivers to identify their needs and develop services to meet them. In 1997, the 'New Labour' government under Prime Minister Tony Blair introduced a 'modernising agenda' for health and social care with the aim of

promoting social inclusion and participation of older people in all aspects of community life and care, and the subsequent NHS Plan 2000 (DH 1998) required NHS Health Trusts and Social Care organisations to define how they would meet the health and social needs of local populations with particular emphasis on meeting the needs of marginalised and minority groups to ensure equality of access to services. The increased focus on improving the quality and standards of services outlined in the National Service Framework for Older People (DH 2001) set out a 10-year plan for service improvement across Health and Social Care services. Standard 7 stated:

> *Older people from Black and minority ethnic communities need accessible and appropriate mental health services. Unfortunately, for a number of reasons services may be neither readily accessible nor fully appropriate (DH 2001:90).*

And the Audit Commission's 'Forget-me-Not' review (2002) highlighted the lack of coherent and specialist services in dementia care for BAME communities, while 'Delivering Race Equality in Mental Health Care' (DH 2005) set out a 5-year plan of action to address the inequalities in mental health care for BAME communities. This plan acknowledged cultural and language barriers and aimed to provide better information, encourage community engagement, and provide more responsive services (DH 2005).

Other organisations such as the Policy Research Institute on Ageing and Ethnicity (PRIAE) attempted to improve the quality of life for BAME older persons by launching the Better Health for BAME Elders Project which highlighted key service gaps and concerns for BAME older people accessing mental health services, producing clear information, conducting focused studies such as Buffin et al. (2009), with targeted policy and service improvements, and attempting to engage older people from BAME communities and organisations. These efforts and research demonstrated yet again the need for statutory agencies to receive training on cultural

competence as well as the need for community-based groups to understand the referral pathways through mental health services. Following dissemination and consultation seminars PRIAE reported that statutory services needed to:

> *…develop more effective engagement strategies with BAME elders and their family caregivers; involve BAME elders in developing mental health policy; and design services in collaboration with BAME elders, their families, the BAME voluntary and community sector, and faith organisations* (Buffin et al. 2009:14).

The continuing challenge of meeting the needs of people with dementia and their caregivers eventually led to the development of the first UK National Dementia Strategy which was published in February 2009. The National Dementia Strategy supported and pulled together the key principles from other key policy documents such as 'Putting People First' (DH 2007), 'Carers at the heart of 21st century families and communities' (DH 2008a) and the 'End of Life Care Strategy' (DH 2008b) and it clearly set out the expectation that local health and social care organisations should jointly plan and commission services on behalf of their local populations.

In June 2009 the Department of Health published the 'Joint Commissioning Framework' which provided guidance on commissioning each of the service objectives set out in the Strategy to improve the wellbeing of people with dementia and their caregivers (DH 2009b). This highlighted the need for commissioners to give particular consideration to people with dementia from BAME communities and the importance of involving family caregivers as well as service providers when developing local implementation plans. The then Prime Minister, David Cameron, gave a new impetus to the Dementia Strategy in 2012 with the Prime Minister's challenge on Dementia, which stated,

> *We must ensure that every person gets the treatment and support which meets their needs and their life (DH 2012:8).*

The first progress report on the Prime Minister's Challenge (DH 2013) highlighted the inquiry findings of the All-Party Parliamentary Group on Dementia (APPG 2013), that I was privileged to be a part of, as a source of recommendations for work with dementia in BAME communities. However, the progress report itself lacked any vision of the communities as integral partners of the strategy when it outlined its approach to funding allocations and stakeholder building. In practice I found that, along with other representatives from BAME communities, we appeared to be gate-crashing discussions that were already well under way, and completely dominated by clinical interests and academic institutions. Nevertheless, the APPG on Dementia's Report (2013) was significant in placing issues for dementia in BAME communities at a national policy and political level not previously seen in any implementation plan.

1.6 Chapter summary

The purpose of this chapter was to set the scene by presenting a profile of the researcher and the motivation for doing this study, and stating the research aim and objectives and the importance and contribution of this study to the existing body of knowledge regarding dementia caregiving within BAME communities. This was followed by background information regarding the Jamaican diaspora situated outside of Jamaica to give a context for the study. Dementia was then defined within several models of health care to illustrate how dementia is understood and the impact this has on how care is delivered. The prevalence and policy developments around dementia in Jamaica and the UK were outlined.

The next chapter presents a review of literature published between 2000 and 2018 to create an overview of dementia caregiving by family members in BAME

communities. This literature will also be used to develop a rationale for the specific research question elucidated at the end of the chapter. Additionally, the homogenising of African Caribbean communities will be considered to highlight the underrepresentation of Jamaican families in research.

Chapter 2 Literature Review

2.1 Introduction

The primary aim of this integrative literature review is to critically appraise published qualitative studies that have explored the lived experience of family caregivers in BAME communities. This approach allowed me to acquire a critical overview of research with African Caribbean caregivers in general and Jamaican caregivers specifically.

As highlighted by Ponterotto (2010), studies focused on caregiving have tended to be conducted within a positivist/post-positivist paradigm, with the dementia caregiving literature in particular being primarily informed by predetermined models. Much of the literature utilises quantitative methods that measure psychological constructs such as stress using standardised scales (Ponterotto 2010). These measuring scales however tend to be limited by predetermined responses, preventing the research from capturing the multi-dimensional depth and richness of personal meanings relevant to the participants' lived experience of caregiving. It seems appropriate therefore that any exploration of caregiving should focus on more than just investigating how families are coping and what they are doing on a day-to-day basis to maintain support; it should also be about understanding the affective and personal motivating aspects of their caregiving experience. Qualitative studies therefore became the primary focus for this review, as this methodology was appropriate for my own research aim which focusses on the lived experience of dementia caregiving by caregivers of Jamaican heritage living in England and Jamaica. Quantitative studies that focussed on empirical measures such as diagnosis rates and cognitive function tests, will not be fully explored in this chapter.

2.2 Search strategy

A systematic approach was used to conduct the literature search using seven internet databases (Table 2:1) to find peer reviewed journal articles published between 2000 and 2018.

1. CINAHL	5. Social Care Online
2. Medline	6. SocINDEX with full text
3. PsychINFO	7. Scopus
4. Google Scholar	

Table 2:1 Databases searched

While databases are recognised as being effective and efficient (Polit and Beck, 2012) they cannot be taken as the totality of available literature and as Green and Thorogood (2018) suggest, it is important to read widely. Therefore, to ensure an extensive search, manual searches were conducted using the reference lists of included studies. Library staff were helpful in sourcing articles that were not in the University stock, and there was extensive background reading of papers and documents around the subject area. In addition, fellow doctoral students, colleagues at the Caribbean School of Nursing at the University of Technology (Utech) in Kingston Jamaica, and colleagues at the Ageing and Wellness Centre at the University of the West Indies (UWI) Mona Campus in Jamaica, notified me of articles and publications referring to the care of older persons in Jamaica.

2.3 Key Terms

The following key search terms were used: (Dementia), (Alzheimer's), (Vascular dementia), (Caregivers) (Carers) (Family) (Lived experience) (BME), (BAME) (African Caribbean). Key words and MeSH terms were used individually and collectively to reduce the data accordingly. As new terms became apparent, these

were added to the search. The review also incorporated an examination of the methodological approaches taken by previous researchers.

2.4 Inclusion/Exclusion criteria

Searches were not initially restricted to specific dates, neither were searches limited to particular countries (although only papers published in English were perused). Table 2:2 sets out the eventual inclusion and exclusion criteria that were applied to identify the most relevant papers. All primary research that explored caregiving experiences with BAME communities were included. Studies were included regardless of whether they compared different ethnic groups. Once an initial examination was concluded a database alert was created to capture any new publications. Only two further eligible studies were identified, and all searches were concluded in September 2018.

Inclusion criteria	*Exclusion criteria*
Qualitative study exploring the experiences or needs of BAME caregivers caring for a family member living with dementia	Quantitative studies Mixed methods studies
Study was published after 2000	Study was published before 2000
Study participants were from a BAME community	Study participants did not include any BAME participants
Peer reviewed and published in English	Meeting abstracts, letters, literature reviews, editorials, correspondence, or conference proceedings

Table 2:2 Inclusion and exclusion search criteria

2.5 Search results

As anticipated, there was considerable overlap and replication of results across databases. A PRISMA four phase flow diagram (Fig. 2:1) presenting the study selection process based on inclusion and exclusion decisions is shown below. Some 23 papers were selected which were then appraised using CASP (2014)

(Table 2:3 Appendix 2:183-194) then reappraised and quality scored using CASP (2018) (Section A Validity) (Table 2:4) on p46.

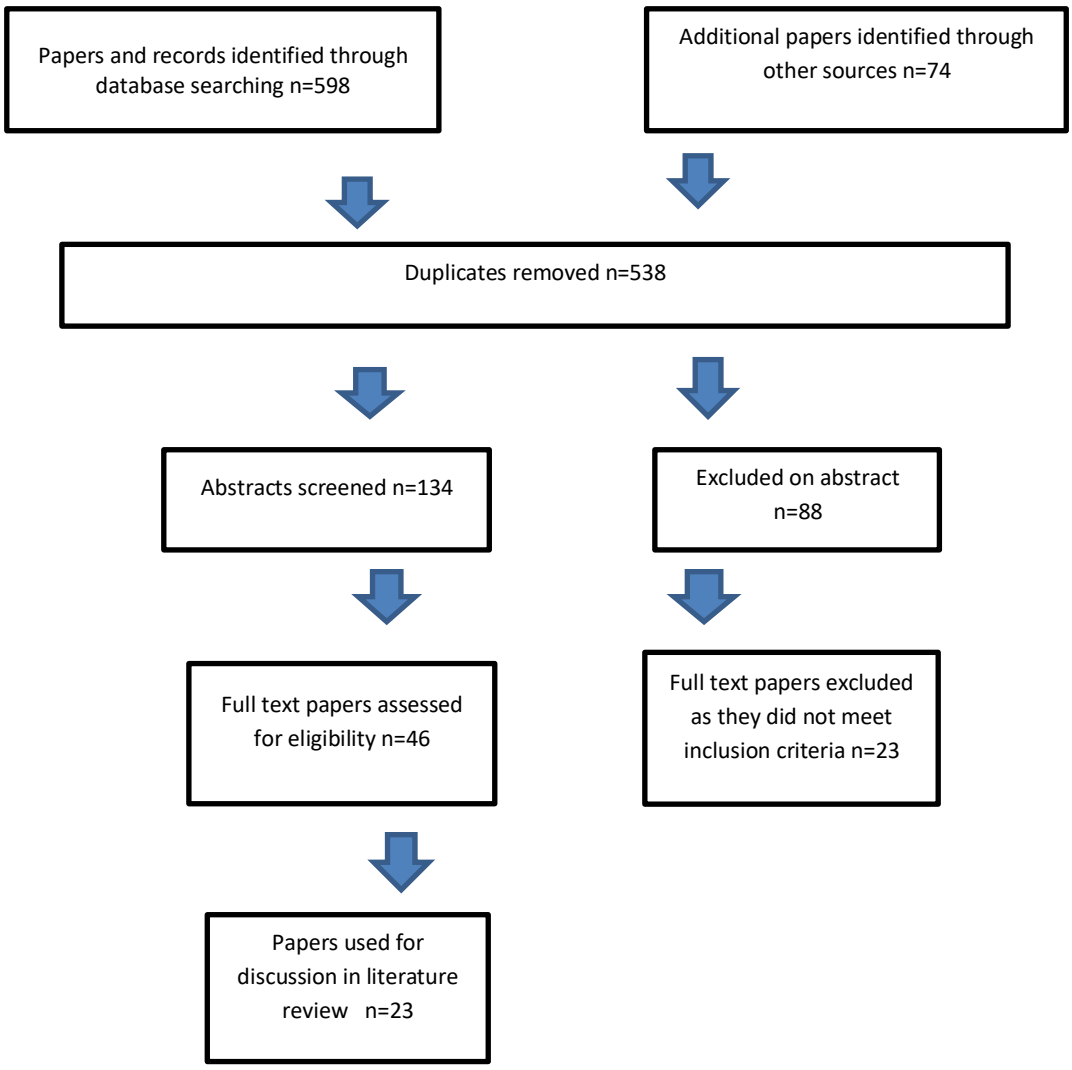

Figure 2:1 Flow diagram presenting the study selection process (Moher et al. 2009)

2.6 Quality Appraisal

Although appraisal checklists are more helpful in quantitative paradigms, it was still essential to determine the quality and appropriateness of selected studies (Thomas & Harden 2008). The use of CASP tools provided a critical framework and a systematic approach to review papers. In completing this process, papers were reviewed closely, and considered as to how each addressed the knowledge base, and my research question around caregiving in African Caribbean/Jamaican communities. The selected papers were initially appraised using the Qualitative Research Checklist developed by the Critical Skills Appraisal Programme (CASP) (2014) which comprises 10 screening items (summarised in Table 2:3 Appendix 2: 183-194) and reappraised using CASP (2018) (Section A Validity) (Table 2:4 below) which comprised the six questions listed below.

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?

Scores were assigned on the basis on one point per item with possible scores ranging from 0 (lowest quality) to 6 (highest quality).

	Papers	1	2	3	4	5	6	Total Score
1	Baghirathan & Cheston (2018)	1	1	1	1	1	1	6
2	Berwald et al. (2016)	1	1	1	1	1	0	5
3	Samson et al. (2016)	1	1	1	1	1	0	5
4	Sun (2014)	1	1	1	1	1	0	5
4	Botsford et al. (2011)	1	1	1	1	1	1	6
5	Mukadam et al. (2011)	1	1	1	1	1	0	5
6	Parveen et al. (2011)	1	1	1	1	1	0	5
7	Jutlla (2011)	1	1	1	1	1	1	6
8	Jolley et al. (2009)	1	1	1	1	1	1	6
9	Lawrence et al. (2008)	1	1	1	0.5	0.5	0	4
10	La Fountaine et al. (2007)	1	1	1	0.5	0.5	1	5
11	Adams (2006)	1	1	1	1	1	1	6
12	Adamson & Donovan (2005)	1	1	1	1	1	1	6
13	Jett (2005)	1	1	1	0.5	0.5	0	4
14	Jones et al. (2006)	1	1	1	1	1	1	6
15	Mackenzie (2006)	1	1	1	1	1	1	6
16	Mahoney et al. (2005)	1	1	1	1	1	1	6
17	Neary & Feany (2005)	1	1	1	1	1	0	5
18	Park et al. (2004)	1	1	1	1	1	0	5
19	Zhan (2004)	1	1	1	1	1	0	5
20	Cloutterbuck & Mahoney (2003)	1	1	1	0.5	0.5	0	4
21	Ho et al. (2003)	1	1	1	1	1	1	6
22	Adamson (2001)	1	1	1	0.5	0.5	0	4
23	Lampley-Dallas et al. (2001)	1	1	1	0.5	1	1	5.5

Table 2:4 Quality Scores using CASP (2018) (Section A Validity)

A partial point was given if a study did not report a recruiter-participant ethnicity match, for example by making use of Black informant/recruiter/interviewer in addition to standard methodology, or if it failed to address the potential influence on the findings of the ethnic discordance between researcher and participant. No study was excluded, but there is limited evidence on how to approach the exclusion of qualitative studies based on quality (Thomas & Harden 2008).

2.7 Study Characteristics

All studies recruited caregivers of people living with dementia. The BAME groups in all studies reflected the ethnic composition of the location in which the studies were conducted (see Table 2:5 below). Some 12 studies were conducted in the UK, 9 in the US, and 2 in Canada.

Author and location	Aim	Number and ethnicity of participants
Baghirathan & Cheston (2018) United Kingdom	To explore the experiences of caregivers from South Asian, African Caribbean, and Chinese communities in Bristol to generate a grounded theory	47 South Asian 31 Chinese 25 African Caribbean
Berwald et al. (2016) United Kingdom	To explore the barriers to help seeking for memory problems with UK Black African and Caribbean communities	28 Black African 14 Black Caribbean 7 Black British 1 Indo Caribbean
Samson et al. (2016) United States	To explore how issues of race and culture can be incorporated into culturally sensitive interventions	32 African American
Sun (2014) United States	To explore stressors and coping strategies of family caregivers living in Shanghai China	18 Chinese
Botsford et al. (2011) United Kingdom	To examine the experiences of partners of people with dementia in two minority ethnic communities	7 Greek Cypriot 6 African Caribbean
Mukadam et al. (2011) United Kingdom	To explore the link between attitudes to help seeking for dementia in BAME communities and the indigenous population	5 South Asian, 1 Asian other 1 White Irish 1 White other 1 Chinese 15 Black (African or Caribbean)
Parveen et al. (2011) United Kingdom	The convergence and divergence of experiences of caregivers from four ethnic groups	8 British Bangladeshi 9 British Indian 4 British Pakistani 9 White British

Author and location	Aim	Number and ethnicity of participants
Jutlla (2011) United Kingdom	To explore how migration experiences and personal histories influence experiences of caring for a person with dementia for Sikhs living in Wolverhampton	12 South Asian
Jolley et al. (2009) United Kingdom	To learn about dementia within BAME groups and how to improve services	10 African Caribbean 20 South Asian
Lawrence et al. (2008) United Kingdom	To explore the caregiving attitudes, experience and needs of family carers of people with dementia from the three largest ethnic groups in the UK	10 Black Caribbean 10 South Asian 12 White British
La Fountaine et al. (2007) United Kingdom	To explore the perceptions of ageing, dementia, and age-related mental health difficulties amongst British People of Punjabi Indian origin	49 British South Asians
Adams (2006) United Kingdom	To explore major concerns and emotions experienced by caregivers of persons recently diagnosed with Alzheimer's disease, and their thoughts about informal or formal sources of help	2 Black 18 White
Adamson & Donovan (2005) United Kingdom	to explore the meaning of being an informal caregiver of an older family member living with dementia for South Asian and African Caribbean caregivers	21 African Caribbean 15 South Asian
Jett (2005) United States	To explore the cultural and linguistic variations in the definition, recognition and explanation of, and response to dementia in the African American community	14 African American
Jones et al. (2006) Canada	To understand the factors shaping Asian American's attitudes towards Alzheimer's disease	23 Japanese American 13 Korean American 26 Chinese American
Mackenzie (2006) United Kingdom	To understand the needs of family caregivers from Eastern European and South Asian groups	11 Pakistani 5 Indian 1 Polish I Ukrainian
Mahoney et al. (2005) United States	African American, Chinese and Latino family caregivers' impressions of the onset and diagnosis of dementia: Cross cultural- similarities and differences	4 Chinese 11 Latino 7 African American* (*1 Jamaican)
Neary & Feany (2005) United States	To explore dementia caregiving in a group of Latino caregivers to identify cultural influences on the caregiving experience	11 Latino
Park et al. (2004) United States	To provide and in-depth description of Korean family experiences making decision for placement of family member in a long-term care facility	19 Korean

Author and location	Aim	Number and ethnicity of participants
Zhan (2004) United States	To explore the experiences of Chinese American caregivers	4 Chinese American
Cloutterbuck & Mahoney (2003) United States	To explore the perceptions and experiences of African American caregivers of family members with dementia	7 African American
Ho et al. (2003) Canada	To explore with Chinese Canadian female caregivers their feelings about providing for relatives with Alzheimer's disease	12 Chinese Canadian
Adamson (2001) United Kingdom	To explore awareness, recognition and understanding of dementia symptoms in families of South Asian and African Caribbean descent in the UK	18 African Caribbean 12 South Asian
Lampley-Dallas et al. (2001) United States	To explore the needs of African American caregivers and their expectations of the health care system	13 African American

Table 2:5 Study Characteristics

2.8 Review of the literature organised by themes

The findings were synthesised around four themes: perceptions of dementia, perceptions of caregiving, female responsibility, and family and community attitudes. However, before discussing these further it is important to discuss a key issue that impacts on the reporting of BAME communities, which is how African origin populations are labelled in the research literature.

2.8.1 Labelling of African origin populations in research

The heterogeneity of African descent populations, South Asian, and White populations has been highlighted by Bhopal (2004), however broader consensus is still needed in classifying African descent populations living in the UK and the US for research studies (Agyemang et al. 2005, Vertovec 2007). African descent populations in the UK, as in the US, are diverse and classifications for such populations are often vaguely defined, while the concepts underlying them are poorly

understood, (Afshari and Bhopal 2002). Table 2:6, together with glossary definitions on page 7 summarises the terms used in the research literature.

Combining heterogeneous African populations under a single label such as 'Black' creates practical challenges of comparability (Kaplan & Bennett 2003) as there is considerable diversity within, and between the African descent populations in UK and in the US. The current groupings of African descent populations in the UK and the US as Black, Black African, African Caribbean, and African American hide the huge heterogeneity within these groups, which weakens the value of ethnic categorisation as a means of providing culturally appropriate dementia care, and in understanding the impact of ethnic differences in its causes and prevalence.

The African Caribbean population in the UK comes mainly from former colonies and the West Indies, whereas in the US African American populations include people from the West Indies, Haiti, and various parts of Africa (Williams & Jackson 2000). These groups are distinct in terms of their culture, beliefs, behaviours, and health risk factors (Agyemang et al. 2005). While self-definition of ethnicity is gaining support in research (Agyemang et al. 2005), one key drawback of this approach is that self-assigned identity may change over time depending on the individual context. I personally experienced the challenge of this at the beginning of this study when I was challenged at my presentation to the Ethics Committee in Jamaica to change the term 'African Caribbean' to specifically state 'Jamaican' in the title of my thesis, a request that on consideration I chose to accede to.

Term	Applied to	Strengths	Weaknesses	Comments and recommendations
Black	Persons of black or dark-skinned race	Used in US and UK censuses: Socially recognised and historically lasting concept.	Used to describe heterogeneous populations. Unrelated to ethnicity.	In practice it refers to persons with sub-Saharan African ancestral origins with brown or black complexion.
African origin	Applies to a native of Africa.	Signifies geographical origin.	Geographically based. Used to describe heterogeneous populations.	This term is currently the preferred prefix for more specific categories, such as African America, African Caribbean Use on its own should be avoided
Black African	Applies to persons and their offspring with African ancestral origins who/family migrated directly from sub-Saharan Africa.	Used in UK censuses. Signifies sub-continental origin.	Very broad Unrelated to ethnicity	Avoid if possible.
African Caribbean	Applies to persons and their offspring, with African ancestral origin but migrated via the Caribbean islands.	Used in censuses Signifies geographical origin Attempts to describe a cultural group	Inaccurate unless it is a truly representative population. Used to describe heterogeneous populations	Useful and preferred if other ethnic groups are not included. Avoid combining other African groups.
African American	Applies to persons and their offspring with African ancestral origin (many are descendants of persons brought as slaves).	Used in USA censuses. Signifies geographical origin. Attempts to describe a cultural group. In practice, North Africans from Algeria, Morocco and such countries are excluded from this category.	As for African Caribbean.	Useful and preferred if other ethnic groups are not included.

Table 2:6 Analysis of terms to describe African origin populations (Agyemang et al. 2005)

2.8.2 BAME Perceptions of dementia

The reviewed studies highlighted that caregivers from BAME communities had culturally based perceptions and levels of understanding of dementia that impacted upon their caregiving experience. Botsford et al. (2011) conducted 43 in-depth interviews with 13 Greek Cypriot and African Caribbean caregivers living in London. It was found that most participants had interpreted the changes associated with dementia as normal ageing. This was expressed through participants suggesting that challenges with memory were a natural result of ageing. Many participants expressed a general belief that cognitive decline might be expected and therefore forgetfulness was a natural part of the ageing process. Botsford et al. (2011) also found that the perception of memory issues being viewed as a normal ageing process was associated with a delay between caregivers noticing a problem and seeking an explanation. While it could be argued that Botsford et al. (2011) highlighted a specific way in which dementia is construed in two BAME communities, limited to only discrete Greek Cypriot and African Caribbean communities in London, the finding that caregivers viewed their family member's cognitive decline as a normal process of ageing is mirrored in US studies by Jones et al. (2006) with 62 caregivers from Japanese American, Korean American, and Chinese American communities. This is also the case in Mahoney et al. (2005) with 22 African American, Chinese, and Latino caregivers, and Cloutterbuck & Mahoney (2003) with seven African American caregivers. An analysis of responses to questions about their perspectives on dementia participants tended to downplay the significance of cognitive and behavioural changes. The finding that carers viewed their family members cognitive decline as a normal process of ageing was further mirrored in the study by Jolley et al. (2009), a UK study conducted over a six-year period with 30 BAME caregivers. Jolley et al. (2009) highlighted that a lack of information and

understanding held by African Caribbean and South Asian caregivers about dementia led them to be unaware of its differentiation from normal ageing. This, coupled with negative experiences of attempting to access primary care physicians for most health concerns, meant that caregivers were found not to seek help or access mental health services until a crisis occurred. The reviewed studies also suggested that, in some communities, caregivers had other unique ways for expressing these behavioural changes. As alluded to in Chapter one, Mahoney et al. (2005:787), in questioning African American, Chinese and Latino caregivers, found that for African Americans it was an *old timers' disease* whereas Latinos used the phrase *el loco* for craziness and the Chinese used *hu tu* for becoming forgetful in old age. Additionally, Chinese caregivers in Mahoney et al. (2005), Zhan (2004) and Ho et al. (2003) all attributed personality changes to bad *feng shui* which had created negative energies.

Another distinct perception was captured by Mukadam et al. (2011) who, using semi-structured interviews with 20 caregivers from African Caribbean, South Asian, Chinese and White UK communities, found that for BAME caregivers a lack of trust in healthcare systems affected their perception that a diagnosis would change their circumstances, and therefore was not perceived as useful. Caregivers from BAME communities viewed the person they are supporting as having symptoms of old age, not as someone with a medical condition that needed support or treatment.

2.8.3 BAME Perceptions of caregiving

Although the term ‘carer’ has gained widespread use it does not appear to be routinely understood in BAME communities (Adamson 2001, Moriarty et al. 2001, Townsend and Godfrey 2001), with many BAME caregivers finding it hard to relate to the term and struggling to distinguish between caregiving responsibilities and normal kinship relations. The failure to adopt an approach that takes account of these perspectives of BAME families only adds to further marginalisation (Milne 2003). This may be a contributory factor in the under-representation of BAME communities in local and national assessments of the extent of caregiving. The terms ‘carer’ and ‘caregiver’ are both used widely across the literature for describing both family and paid professionals employed to provide care (Afiya Trust 2008). Molyneaux et al. (2011) compiled a range of evidence of non-identification with the term *carer* in various contexts, not just in BAME populations, and found that the term negatively impacts the identity of the person being cared for, and the person doing the caring. Thus, they challenge the increasing universal adoption of the term. Molyneaux et al. (2011) support the views of O’Connor (2007) about the negative impact of this service-user driven terminology upon families’ experiences of caring, and they argue that the use of the term ‘carer’ has transformed the concept of care; from a phenomenon pertaining to a ‘verb’ to that of a ‘noun’. Their suggestion is that the action of caring (as a verb) has become a ‘role’ or a ‘position’ (noun) of a carer, which objectifies and detaches people from their traditional kinship relationship. This shift, according to Calderbank (2000) and Harding and Higginson (2001), from perceiving caring in the context of a kinship relationship to one that emphasises people as carers, appears to have created unnecessary interference and detachment in the relational experience of caring. It is further argued by Fine and

Glendinning (2005) that the term ‘carer’, which originated in the context of questioning the social norms in which women mainly undertook caring, has shifted the perceptions of caring from those emphasising caring as a choice, to seeing it as an imposition. Dean and Thompson (1996:151) suggest that, paradoxically, de-emphasising the option to care has contextualised a conceptual shift in the perception of caring. They claim it has become ‘fetishised’ through the process of modifying familial dependency in transferring the responsibility of care to services, and the subsequent normalisation of the ‘informal’ carer as a commodity to reverse public expenditure. Dean and Thompson (1996) argued that caring had become ‘ideologically distorted’, and that the political and economic movement of services has pressured families towards an obligation to provide more and more care without offering appropriate supportive options, and by so doing isolating those doing the caring. In this context, though, it is worth noting again that in Jamaica, care for older relatives is legislated within the Maintenance Act (2005) as normal expected kinship caring, familial duty, and obligation, and that community – non-resident and non-kinship – caring would represent a different type of involvement and experience from a person caring for a relative they lived with and were related to as mentioned in the previous chapter.

All studies stated that there were positive and negative aspects of the caregiver role and all have highlighted the strengthened bond between themselves and their care recipient as the main positive aspect. They reported that the role was made more difficult by them occupying multiple roles such as spouse, employee, or guardian to other dependents. What was not well articulated in the reviewed studies was an explanation as to why some caregivers exhibited more adaptive responses to stressful experiences, although other studies by Haley et al. (2004) and Coon et al.

(2004), which take into account demographic variables, such as age, economic status, marital status, education, wellbeing and religious beliefs, found that African American caregivers were less likely to experience stress or a sense of burden tending to appraise caregiving more positively and report less anxiety in their role in comparison with white caregivers. However, it should be noted that much of the evidence discussing the challenges of caregiving appears to have come primarily from white participants, (Lawrence et al. 2008).

Dealing with the challenges of being a caregiver for a family member with dementia has been linked to psychological stress, feelings of being trapped in the caregiver role, and being overwhelmed by the demands of providing care, which can have a considerable effect on psychological wellbeing. Some caregivers had given up employment, social contact with colleagues, friends, hobbies and leisure pursuits. Milne and Chryssanthopoulou (2005). Haley et al. (2004) identify African Americans as having a significantly greater ability to manage the emotional and physical demands of caregiving and to protect themselves from the associated negative consequences. Furthermore, they are less likely to view caregiving as intrusive, tend to hold more positive views about the obligation to care, and are able to retain their sense of self. Knight and McCallum (1998) suggest that this may be the result of African American caregivers' adoption of a positive mental strategy. They argue that adaption to long-term oppression, segregation, and socio-economic deprivation has resulted in the reframing of difficult life experiences, equipping African Americans to deal more effectively with the demands of caregiving. Adamson and Donovan (2005) interviewed 36 caregivers from African Caribbean and South Asian communities across numerous geographical locations in the UK. Using in-depth semi structured interviews, the study aimed to discover the meaning of being a caregiver for a family

member living with dementia and a grounded theory approach highlighted that participants viewed caregiving as a normal feature of their life, which was often a continuation of their identity. The perception of caregiving as an extension of an existing responsibility was also evident in the study by Lawrence et al. (2008:731), which compared the experiences of 32 White, African Caribbean, and South Asian caregivers from London, all caring for a family member living with dementia. In-depth individual interviews found those caregivers with 'traditional caregiver ideologies' saw caring as natural, expected, and virtuous, and also that strong religious values motivated and shaped the desire to support a family member. Daughters and sons of South Asian origin were most likely to explain this in terms of caregiving as a cultural norm and as an opportunity to reciprocate parental support. This account of caregiving as a cultural norm was missing from the accounts of white sons and daughters caring for their parents in the study (Lawrence et al. 2008). The finding of caring being culturally bound was further supported by Botsford et al. (2011) and Adamson and Donovan (2005) which, in a similar vein, also describe how caregivers often viewed caregiving as an extension of their family responsibilities. However, despite highlighting how caregivers situate their role as a cultural norm, Adamson and Donovan (2005) did not explore the factors that might account why this may be the case.

Research from the US also highlighted the important role that spirituality and religiosity play in supporting African American caregivers (Haley et al. 2004, Navai-Waliser et al. 2001). It is also argued by Farran et al. (2003) that religious belief provides an explanatory framework, resulting in greater acceptance of the challenges of caregiving and caregivers' ability to manage stress. In their study, Levine (2003) found that African American caregivers were happy to state that

prayer was part of their toolkit for coping, despite counter-arguments from Cloutterbuck and Mahoney (2003) who argued that religion did not appear to be as important for caregivers, and that the role of the church as a source of support was diminishing.

2.8.4 Female responsibility for caregiving in BAME communities

The general tendency of responsibility for caregiving falling predominately on female caregivers within BAME communities was reported in many of the papers reviewed. The main caregivers were usually identified as a daughter or daughter-in-law. Jutlla (2011) for example, found that, when providing care for someone living with dementia in a Sikh household, there was an expectation for the daughter-in-law to provide the care, adding to the incidence rate of hidden carers in Sikh families. It was also found that females held an existing care identity, perhaps due to care being more consistent with the socialized female role. This would suggest that females may have already been providing a caring role for the person living with dementia before they developed dementia. This contrasted with male caregivers who exhibited a change of their current identity into a caring role which they had not previously identified with (Jutlla 2011). A similar finding was present in a study by Adamson and Donovan (2005) who interviewed 21 African Caribbean and 15 south Asian caregivers of a family member living with dementia. This grounded theory study found that female caregivers felt a stronger moral obligation to care than male caregivers (Adamson and Donovan 2005). In line with these findings Botsford et al. (2011) identified the expectation that daughters would provide care for the person with dementia. This tendency was found to be more prominent in a Greek Cypriot community than in an African Caribbean community. The findings from Adamson and Donovan (2005) appear to relate to Jutlla (2011) and Botsford et al. (2011) of

females holding an existing moral obligation to care that is not as prevalent in male family members. However, what is unclear from these findings is whether the female care responsibility can be solely explained by gender differences or also due to being part of a BAME community. In a similar vein Ho et al. (2003), who interviewed 12 female Canadian Chinese caregivers, found that they all felt an obligation to provide care. This was consistent with Jones et al. (2006) who found that Chinese and Filipino American female caregivers had been raised to accept responsibility and to see caregiving as an obligation and a cultural and moral mandate. In African American families it can be argued that there is also a powerful expectation that families will provide care for their frail elderly relatives, including those with dementia. Cloutterbuck and Mahoney (2003) noted in their study of seven African American participants that, although the majority of caregivers are daughters or daughters-in-law, care is often shared within a family network and it is acceptable for caregiving to be shared by a range of relatives, including spouses and sons. Caregiving support is also received from the wider family or community and contact with others is encouraged (Dilworth-Anderson et al. 2002). These findings were also in line with Milne and Chyssanthopoulou (2005) who identified a cultural role among females from Black and South Asian communities who provide most of the caregiving for someone living with dementia.

2.8.5 BAME family and community attitudes

A number of studies – Mahoney et al. (2005), McKenzie (2006), Zhan (2004), and Ho et al. (2003) all reported that problems relating to caring were often purposely hidden to avoid community awareness, and all groups withdrew somewhat from the wider community network when someone in the family developed dementia. Their reasons were, however, very different. East and Central European participants

stated that they wanted to hide the illness, because they felt that Polish and Ukrainian communities were frightened of dementia. African American participants suggested it was to protect the dignity of their elders. Only Indian participants perceived dementia as more easily tolerated in the community, because the lack of understanding about dementia meant it was generally thought to be related to old age, and the wider community were not interested in dementia until it personally affected them. Although it has previously been assumed that South Asian families have a large extended network of family members who look after their own (All Party Parliamentary Group on dementia, 2013), South Asian participants in Mackenzie (2006) and Parveen et al. (2014) stated that wider family networks were not always supportive. In some cases, they perceived the stress caused by family members to have actually caused the dementia.

Mackenzie (2006), Lawrence et al. (2008) and Parveen et al. (2014) all highlighted the value held by family members of being able to care for their relatives living with dementia, and the feeling that placing their relative into a care facility would cause them to encounter stigma or a feeling of failure. African Caribbean and African American participants appeared to hold such strong respect for elders that this supported tolerance of behavioural deviations and there was strong extended family support to help elderly family members.

2.9 Gaps in the literature and rationale for study

The issue of homogenising African Caribbean caregivers in research studies highlighted the underrepresentation of Jamaican caregivers. Only one study (Mahoney et al. 2005) carried out in the US specifically identifies one single participant as being of Jamaican heritage, although it is possible that other caregivers of Jamaican heritage have been participants in studies.

Milne and Chryssanthopoulou (2005) have drawn attention to the requirement for such much-needed research, and although a few significant studies have been done focusing on BAME communities (Lawrence et al. 2008; 2010, Jutlla and Moreland 2009), it is the studies conducted in the US that provides much of the evidence for our understanding of dementia and caregiving in communities of Black African descent. Although there are a number of studies conducted in the US and UK, there are no studies conducted in Jamaica. The complex and evolving context of caregiving as already described, demonstrates the potential for both disjunction and innovation. Further research is required to ascertain how dementia is constructed and conceptualised by qualitative exploration of African Caribbean, and particularly Jamaican caregivers caring for a family member living with dementia, as this is not evident in the current literature. Therefore, this study addresses the following research question: What is the lived experience of dementia caregiving by women of Jamaican heritage?

2.10 Chapter summary

This chapter presented a critical review of the academic literature exploring the experiences of dementia caregiving by family members across a variety of BAME communities. A systematic approach was used to explore the literature which highlighted several complex and culture bound factors which characterise the issues and challenges of dementia caring in BAME communities. These included how dementia is conceptualised in BAME communities as part of normal ageing, how the role is caregiver is seen as a natural life progression, and how caregiving may be seen as a way of repaying the care they had received previously from the family member now living with dementia.

In relation to whether or not caregivers are likely to access mental health services for support, the findings suggested that they may not initially identify a need for support, and even when faced with crisis the mistrust, negative experiences, and racism impact on the willingness and ability to access. Given the paucity of qualitative literature around dementia caregiving within BAME communities, (database alert had identified only two further eligible studies between 2013 and 2018), and the evidence from Chapter 1 that Jamaicans living in England and across the diaspora retain strong links with their cultural roots and heritage, the next chapter outlines the methodology for my qualitative study to offer a unique and original contribution about dementia caregiving in Jamaican families. Using in-depth interviews that explores the lived experience of women of Jamaican heritage living in England and Jamaica will allow for an expansion to the knowledge base, will improve theoretical debates on the perceived needs of this cultural group, will harmonise policy implementation of the Dementia Strategy in England (DH 2009), and assist in the development of a dementia strategy for Jamaica.

Chapter 3 Research methodology and method

3.1 Introduction

The philosophical approach and theoretical framework for this study centred on my wish to explore the lived experiences of women of Jamaican heritage living in the UK and Jamaica to ascertain what could be learned to build a knowledge base. I was interested in the various ways they might be positioned and seek to position themselves through their caregiving experiences. I therefore approached the research from an interpretivist perspective that ontologically is comfortable in the belief that realities are multiple, and epistemologically that knowledge making is grounded in experience and shared subjectivities. Section 1 of this chapter discusses my philosophical position. Section 2 describes the theoretical framework, underpinning the research approach adopted for this study. how participants were recruited to participate in the study. Section 3 details the ethical considerations brought to bear on the research process. Section 4 describes the data collection procedure. Section 5 explains the approach to data interpretation. The chapter concludes with a discussion of the importance of my research diary to support a reflexive approach throughout the research study.

3.2 Epistemological and ontological positioning

Originating from the Greek word episteme (Trochim 2000), epistemology examines how we know what we know and what counts as knowledge. It is characterised by two predominant paradigms, broadly positivism and interpretivism. The positivist paradigm adopts a realist stance where the researcher examines independent facts about a single apprehensible reality (Lincoln and Guba 2000). Inherent in this perspective is the belief that phenomena have intrinsic meaning and as such

knowledge is fixed, stable and follows immutable laws. Language is unproblematic according to this perspective, as words are believed to reflect knowledge that is objective, unbiased, reproducible, and accessible if an appropriate method of inquiry is used (Lincoln & Guba 2000). Key in this paradigm is that positivists separate themselves from the phenomena under analysis, creating reliable science that can be reproduced. The interpretivist perspective is interested in exploring the meaning people attach to their experiences and how these meanings are created, negotiated, and sustained, (Schwandt 2003).

Ontology is concerned with the nature of social reality, specifically what is the nature of existence and what is there to know about the world. Key ontological questions within social research concerns whether social reality exists independently of human interactions and interpretations. Ontology considers whether there is common shared social reality or just multiple realities, and whether social behaviour is generalisable, (Snape and Spencer 2003). The ontological assumption of the interpretivist paradigm is according to Lincoln and Guba (2000) based on the idea that reality is complex, holistic and context dependent. It focuses its investigation on the cognitive and affective components of human experience. Subjectivity rather than objectivity is therefore given greater emphasis.

Ponterotto (2010) raises an interesting and critical debate about positivist approaches being elevated to such a level that is often portrayed as the only epistemology, with hermeneutics, aesthetic, critical, moral, creative and other forms of knowledge somewhat neglected, an assertion that is supported by the evidence of many studies around caregiving perused in review for the previous chapter. Barbour (2014) argues that, while not denying the many points of departure between

positivism and interpretivist approaches, the break is not as clean or as neat as some commentators would suggest.

I have come to appreciate that previously held epistemological stances more reflected the clinical practice roles undertaken, and the expectations of 'research' within those roles, rather than necessarily being rooted in any personal beliefs or worldview. With this in mind and acknowledging that all epistemological stances have weaknesses and underlying assumptions, a re-examination helped resonate a more personal positioning, a dilemma referred to by Barbour (2014:29) as 'a paradigm war'. For this, reflexivity as defined by King and Horrocks (2010) required me to look both inwards and outwards in critical self-reflection as to how my background and positioning might impact the process, and where I *actually* needed to get to, to undertake *this* study.

Willig (2001:10) suggests that there are two types of reflexivity, personal and epistemological:

> *personal reflexivity involves reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. It also involves thinking about how the research may have affected and possibly changed us as people and researchers, and epistemological reflexivity encourages us to reflect upon the assumptions (about the world and about the nature of knowledge) that we have made in the course of the research, and it helps us to think about the implication of such assumptions for the research and its findings.*

Similarly Finlay and Gough (2003:108) describes reflexivity as "*a continuing dynamic and subjective self-awareness,*" and Holmes (2010:140) defines reflexivity as an:

> *emotional, and cognitive process in which social actors have feelings about and try to understand and alter their lives in relation to their social and natural environment… and it is not only conversations with and about others that are crucial, but embodied practices and feelings. The reflexive self is formed by*

emotional relations with others and thus emotions play a more complex part in deliberations in helping us form and maintain commitments to our projects

Within this study, I also reflected on my position as a Registered Nurse with professional knowledge and understanding of dementia but also a woman of Jamaican heritage with previous experience as a caregiver for a family member with dementia. I acknowledged that this position afforded me some intuitive understanding of the participants' situation as caregivers. Additionally, I was conscious of the issues of insider perspectives and shared experiences that could have promoted bias during the analysis process which, in turn might reflect on the trustworthiness of the study. Butt and Moriarty (2004) highlighted that studies that involve minority ethnic participants generate richer data when the researcher and participants are culturally/ethnically matched, but the methodological issues for Black researchers working within their own community raised by Serrant-Green (2002) were also reflected on in which she states that while being a Black person might be viewed as advantageous in that, apparently, it could ease some of the perceived issues concerning access and familiarity with the lives of the study group, the need for the researcher to make strange the familiar and, the familiar strange, means occupying the dual position as both insider and outsider. As an insider researcher there were both advantages and challenges, and Heugten (2004) suggests that bias and subjectivity, due to insider status can be ameliorated by remaining honest and open about difficulties that arise and diligent self-examination.

Reflexive transparency was achieved by keeping a journal and engaging in reflexive discussion using Action Learning sets with a cohort of peers also undertaking a Professional Doctorate. These processes and actions involved making my beliefs, positioning, and any preconceptions which may have influenced the research

process at different levels, visible to me, and for others to review. Keeping a journal was not only good practice as recommended by my supervisors but as noted by Heugten (2004), it caused me to be aware of the knowledge and skills that I was gaining in the wider research environment.

Reviewing the academic and professional gaps in knowledge identified in Chapter 2, I then considered the aim of the study and what it was seeking to address. The aim of the research was to explore the lived experience of caregivers of Jamaican heritage living in England and Jamaica caring for a relative living with dementia. Understanding the experience is what was being sought rather than empirical knowledge. A phenomenological approach was chosen after in depth examination of my epistemological and ontological beliefs and how these impacted on positioning for my study.

3.3 Rationale for Interpretative Phenomenology (Heideggerian)

Phenomenology and other approaches including feminism (Crawford and Unger 2004), social constructionism (Burr 2006), and Hermeneutics (Schwandt 2000) in different ways have questioned or rejected the idea of an observable independent reality with the person responding to external and internal influences. Phenomenological research essentially seeks to interpret actions and behaviours, and the relationship between person and context is more fluid and reciprocal with influence in both directions (Braun and Clark 2013). Humanists and feminist researchers refute the possibility of starting without preconceptions or bias, and emphasise the importance of making clear how interpretations and meanings have been placed on findings, as well as making the researcher visible in the frame of the

research as an interested actor rather than a detached and impartial observer (Mauthner & Doucet 2003, Gray 2008).

Phenomenology is the study of the structure and the variations in structure of the consciousness to which any- thing, event, or person appears. Phenomenology supports the re-examination of a taken-for-granted experience and, through examining the qualities of the experience, allows us to identify its essence. Therefore, the goal of phenomenological research is not to describe a grand theory or develop a model but to describe what it is like to live the experience. Balls (2009) supports this view when he describes phenomenology as focusing on conscious experience, therefore, a phenomenological approach was chosen because, as van Manen (2002) asserts, it is the most powerful method for understanding experiences, gaining insights into people's motivations and actions, and cutting through the clutter of assumptions. Conklin (2007) states that phenomenology aspires to access the personal, the individual, and the variations within themes. It is inherently a means of creating knowledge that is particular and focuses on the participants' experiences and meaning as experienced by them, rather than on keen descriptions of overt actions or behaviours by the researcher. Meaning, asserts Conklin (2007), takes place at the intersection of the physical world in which experience transpires, and the mental and emotional world of the participant. The core of phenomenology is intentionality, which refers to the notion that consciousness is always the consciousness of something, though not necessarily a physical object; it can be consciousness of a perception. Strawson (1994) explains the notion of intentionality by using an illustration of the phenomenological difference between hearing speech in a language one does not understand and hearing speech in a language one does understand. Two people can be side by side hearing the same spoken sequence of

words, with one of them understanding the language and the other one not. At a relatively raw sensory level, their auditory experience is phenomenologically the same; the sounds are the same, and they may be experienced in much the same way, yet it is obvious introspectively that there is something phenomenologically very different about what it is like for each of them. One person understands the experience, with the distinctive phenomenology of understanding the words, while the other does not. The phenomenological approach in this study focused on participants' views of *their* day to day lives, and *their* lived experiences as caregivers. Heidegger (1927/2011:58) described phenomenology as meaning "to let that which shows itself be seen in the way in which it shows itself". Using a phenomenological approach allowed me, the researcher, to explore the participants' view of caregiving as they understood it. Heidegger (1927/2011) argues that everything is interpretable, but this interpretation is tentative and not the final and absolute answer to truth. Heidegger (1927/2011) writes further that for any interpretation to occur there must be prior experiences of the interpreter. The idea of bracketing (LeVasseuer 2003), a commonly used term in descriptive phenomenology based on Husserl, is rejected, as Heidegger maintained that most researchers already have background knowledge about the focus of their inquiry. This approach accommodated my position as a person of Jamaican heritage, with professional knowledge of dementia and personal experience of family caregiving. Not only does this approach give voice to the participants to share their experience, but by placing priority on the phenomenon of the lived experience of Jamaican women caregivers, it acknowledges insider perspectives during the research process. This approach may enable a better understanding of what the participant feels and how they experience coping with their caregiving role. It also helped me as the researcher to understand

and present choices made and the reasons behind them. By taking this position, there was a philosophical fit between the research paradigm adopted and the chosen methodology.

3.4 Method

3.4.1 Ethical considerations

3.4.1.1 Gaining ethical approval in England and Jamaica

Ethical approval was obtained according to the protocols of the School of Health and Wellbeing at the University of Wolverhampton in England, by paper submission to its Ethics Committee, (Appendix 3:198-233) and approved (Appendix 3:196), and by personal presentation to the Ethics Committee at the College of Health Sciences at the University of Technology (UTech) in Kingston Jamaica (Appendix 3:224-231) and approved (Appendix 3:197).

Appropriate risk assessments were undertaken, and no legal risks or liabilities were identified or envisaged in conducting this study. The study was granted access and support from the Dean at the School of Health and Wellbeing University of Wolverhampton, England (Appendix 3:220) and the Associate Dean at the College of Health Sciences, at the University of Technology (Utech), Kingston, Jamaica (Appendix 3:222-223). The research base while in Jamaica was agreed as the Caribbean School of Nursing at Utech in New Kingston, which also addressed the issue of safety while travelling alone and working in community settings abroad, by establishing a reporting base.

3.4.1.2 Informed consent and confidentiality

To enable potential participants to make an informed decision, as advised by Seymour and Skilbeck (2002), an introductory letter of invitation (Appendix 3:209) to interested participants together with an information sheet was drafted by the researcher under the guidance of supervisors (Appendix 3:211-214) explaining the purpose and context of the study; the reason for their requested participation; what participation would involve; an assurance of confidentiality; what would happen to the data, who would have access to it and where it would be stored. The information sheet included email contact, and by using a dual sim mobile phone, phone telephone numbers to reach me in England and Jamaica. The information sheet also advised all participants would be given time to consider any involvement and encouraged them to discuss with family members or friends before contacting me to take part. This information was made available to caregiver support groups by personal visits, and by post following an invitation to do an interview to promote the study on BBC local radio in the West Midlands.

For the caregivers who agreed to take part in this study, I met with all participants (in both countries) prior to the interviews to answer any questions and to complete consent forms (Appendix 3:216). The lack of free and informed consent in any study is not only unethical (Taylor & Taylor 2014), it means that a study should not take place as it would impact on the trustworthiness of any information obtained. Although there were no issues with any of the participants' literacy or comprehension of English, full verbal explanation was offered. Two copies of the consent form were made, one to be given to the participant and the other kept for my file. Participants were reassured that sharing their experience was to be entirely their decision, but

they were again encouraged to discuss with other family members and friends before taking part. It was also made clear that a decision to participate but later withdraw would not affect any support they would receive. The consent form clearly stated that participation was voluntary and that if participants decided to withdraw at any time there would be no negative consequences for them. It was also made clear that they had the right to withhold any information that would make them feel uncomfortable or cause upset. No monetary compensation in the form of expenses or otherwise was offered to any participant. As all the eventual participants provided consent, none were excluded from the study on this basis.

Participants were fully informed about the confidentiality of information as well as its limits. An important limit on confidentiality conveyed to each participant was that, according to my professional Code of Conduct (Nursing & Midwifery Council (NMC), 2015) I would be obliged to share information if I thought a participant, the person they were caring for, or any other vulnerable person, was at any risk of harm. They were made aware that although quotes might be used in the final write-up of the thesis, all identifying information would be removed. The consent form outlined the location of the data analysis and offered an assurance that the information obtained would not be passed on in recognisable form to anyone within or outside of the study. Interviews were to be conducted in private, at locations either in the participant's home, or at a mutually agreed venue with no one else present during recording. Confidentiality would be maintained in this study by not divulging information to anyone other than those persons directly involved with the study, i.e., my research supervisors in England. No person other than myself can link the interview recordings or notes to any participants, as all data was anonymised using codes on all interview notes and transcripts. Data were protected by the electronic

uploading of interview recordings and transcripts both in England and Jamaica directly to a secure server at the University of Wolverhampton, limiting physical transit. Once this study has been examined, all audio recordings, transcripts, and notes will be destroyed in accordance with University regulations, when advised by research supervisors.

3.4.1.3 Data storage

All data collected was kept securely in encrypted files on a password protected laptop computer accessible to me only. Data confidentiality was preserved throughout by giving numbers to each participant, which were used throughout to prevent individuals being recognised in any of the research documents. The collected data were stored and organised in a project file on the University licensed NVivo programme. (NVivo is discussed later). Any information from this study used to disseminate the outcomes, through conferences, publications, and public presentations is, and will be, anonymised to protect participants.

3.4.2 Data collection

3.4.2.1 Negotiating access

The setting for this study had two bases, England and Jamaica. In the initial design of the study it was planned that in England access to participants would be through dementia support groups run by the Alzheimer's Society UK in and around Birmingham, while in Jamaica it would be through Alzheimer's Jamaica in Kingston and Mandeville. I was not at this point at all conscious that the study population might be difficult to locate. Purposive sampling strategy as outlined by Jarman et al. (2005) was envisaged with support groups being visited and given information about

the study and interested participants being invited to contact me. Several appropriate groups were identified, and visits arranged, in both England and Jamaica, to discuss the study. I undertook poster presentations of the proposed study, attended community and church health events to promote the study, did an interview on BBC local radio, and facilitated a workshop at the Blackness in Britain Conference (Bailey 2013). In Jamaica, following meetings with Prof Eldemire-Shearer at the University of the West Indies, who was a policy advisor to the Jamaican Government regarding older people, I was introduced to the coordinators of the (only) dementia support group in the capital city of Kingston. Being supported in this way expedited the process of trust and acceptance by families, who normally were very reluctant to share anything about dementia caregiving with anyone outside of the immediate family. As an outsider/insider within this community having gained their trust I realised I was in a very privileged position.

Following this preparatory work, recruitment began in November 2013 with an estimated twelve months envisaged for the interviews with caregivers' in England and Jamaica. Recruiting for research studies is time-consuming and is reported to be particularly difficult among BAME communities (Halcomb et al. 2007, Rockliffe et al. 2018). In developing this study I quickly learned that I would need to develop a recruitment strategy for the different settings of England and Jamaica using strategies as proposed by Waheed et al. (2013) and Moorley & Corcoran (2014) of a settings based approach of places of worship and social spaces. This is because of the importance of the church community in the lives of Jamaicans. Church leaders were contacted and I was invited to discuss the study with regard to ethical concerns, access to families who would be willing to talk to me openly about dementia, and the logistics of doing the interviews. Snowball sampling (Richards

and Morse 2013) was then explored using these contacts. Snowball sampling is a non-probability sampling technique that is appropriate for use in research where the members of a population are or become difficult to locate. Snowball sampling "takes advantage of social networks and the fact that groups tend to hold characteristics in common" (Burns and Grove 2004:307).

Although gaining access was initially challenging and frustrating the snowball effect became evident as the number of volunteers for participation increased. Two participants based in England, and one based in Jamaica, told other families that they had participated and recommended others to consider doing the same as they deemed me credible and trustworthy.

3.4.2.2 Inclusion criteria for recruiting participants

As discussed in Chapter 2, the issue of homogenising African Caribbean caregivers in research studies highlighted the under representation of Jamaican caregivers. This study was aiming to specifically address that gap, therefore participants recruited were required to meet the inclusion criteria in that: (a) they were over the age of 18 years; (b) they identified themselves as Jamaican or of Jamaican heritage; (c) they were related to the person being cared for; (d) they had been providing care to their family member for ideally a period of 12 months or longer; and (e) they identified themselves as the main caregiver although other people might have been involved in providing care at some level.

3.4.2.3 Participant descriptors

All the care-recipients in this study were Jamaican by birth. All the caregivers were Jamaican heritage by birth or heritage, born between 1955 and 1965; 5 were graduates in professional occupations. Nine caregivers maintained paid employment for at least 15 hours each week. All the caregivers were women: caring for a mother (n=7), caring for a brother, after caring for a parent recently deceased (n=1), an aunt (n=1), and caring for both mother and father (n=1). Seven of the caregivers lived in the same household as the care-recipient while the other three lived nearby to the recipients, acting as primary caregivers, while sharing care with other family members. One care-recipient moved on to receive care in a nursing home, but all the others remained in their family homes. In England, two caregivers had paid help assisting with care for approximately six hours each week. In Jamaica, two caregivers had paid helpers in the home assisting with housekeeping, but no one had paid help to assist with care. All the care-recipients were church members with three regularly using day services for older members, and five attending Lunch Clubs at least one day each week.

Specific characteristics concerning age, level of education and work history were discussed but not recorded as part of the write-up as the participants' all requested that no details should be included that would identify them, even with the use of pseudonyms. To protect the identity of study participants', pseudonyms are often used in qualitative studies, rather than study numbers or codes to represent the human facet of the research (Allen and Wiles 2016). As part of the doctoral supervision I received it was suggested having pseudonyms and pen-picture profiles to personalise each participant. Ethical protocols were followed inviting each

participant to choose a research pseudonym, but all refused and asked that all possible identifiers be removed from the final write-up. They felt that not using pseudonyms would enable some distance from their transcribed stories. The power of re-reading their stories was illustrated by the profound emotional responses of two caregivers when they reviewed their interview transcripts. I therefore adhered to the participants' wishes and eliminated all identifiers (names and exact ages) to maintain their anonymity.

3.4.2.4 Preparation

Collection of data in phenomenological research is often through interviews, but may also include observations, examination of artefacts and other materials where appropriate. For this study interviews were chosen as the main data collection source because according to Kvale and Brinkmann (2009) a phenomenological interview attempts to obtain descriptions of the participants' lived world, and comes close to an everyday conversation, but as a professional interview it has a purpose, and a specific technique. It can be semi-structured, neither an open everyday conversation nor closed questions, and is conducted according to a guide or prompts that focus on certain themes or may include suggested questions. For this study a set of prompt questions around topics to be explored was developed, (Appendix 3:218) based on issues which were identified from the literature. The order of these could be changed in response to how participants flowed in the telling of their experience. Interviews were envisaged to last no more than 60 minutes. Researchers conducting interviews must become quite skilful to elicit information in the detail needed (Connelly 2010). It is therefore very important to the process to be able to sensitively and reflexively set up the conversations (Swinton and Mowat

2006:61) as "*the way in which the researcher responds, the follow-up questions asked, the researcher's intonation, their eye contact and body language will profoundly impact the way in which a participant tells their story, and the way in which the story is heard by the researcher*". Following guidance from my research supervisors, two practice interviews were done to explore the questions, the flow of the conversation, gauge clarity of responses, and to ensure that they were open, inviting and not leading in any way. It was also important for me to be confident and proficient with use of the audio equipment. In particular it was important to test how to record and upload interviews correctly before travelling abroad. After the two practice interviews and the first two study interviews, one in England and one in Jamaica, I felt comfortable enough with the process to use a grand tour question: 'tell me about your experiences as a caregiver' with clarification and questioning enhanced through the use of prompt questions as necessary.

3.4.2.5 Conducting the interviews

The social context in which the interviews took place and the setting, were important factors considered prior to conducting the interviews. The reason being, as Creswell (2013) indicates, that participant responses may be influenced by these dynamics. For this study all participants were interviewed in a setting that was comfortable for them and at a time convenient to them. For all interviews I telephoned on the morning of the appointment to confirm caregiver was happy to proceed. This process was easier while in Jamaica as I was away from my day job and could be more flexible in my working day but also increased the importance of using a 'safety buddy' alert (Boynton 2005:125). The 'safety buddy' system worked by letting a colleague at Utech Caribbean School of Nursing know my movements around data collection, and my agreement to check in at agreed times. The use of a dual sim mobile phone with a local number was again invaluable.

Gaining access to these family caregivers had required the development of a great deal of trust and it was important that I was honest and open with participants about this study as I was, after all, part of this community. Before each interview, as well as explaining to the participants that they could share as much or as little as they felt comfortable with, it was also outlined that if there were any aspects of their experience they did not want to discuss they could let me know. I understood very clearly the issues around privacy and dignity in the Jamaican community, and knew I was privileged that these caregivers were so willing to even speak with me about their caregiving experience.

Due to the personal nature of the conversations, some of the participants did find it upsetting and became distressed when speaking about certain issues, as for some there had never have been any previous outlet for sharing their experiences. Using a combination of guidance from a Distress Protocol for Qualitative Data Collection (Haigh and Witham 2013) (Appendix 3:232-235) together with extensive experience as a Mental Health Practitioner accustomed to working with people in distress, I endeavoured to conduct the interviews as sensitively as possible. Interviews were envisaged to last no more than one hour but actual timings were between 53 minutes, and 1 hour 45 minutes.

3.4.2.6 Recording the interviews

The interviews, where participants gave permission (n=9), were audio-taped using a digital recording device, to prevent information being lost and to ensure that the interviews could be accurately transcribed later for analysis. One participant in Jamaica withdrew agreement to have their interview audio-taped but was happy for written contemporaneous notes to be taken.

The recorder was placed openly on a table nearby. Questions regarding demographics were asked without the recorder on, to ease participants into making the transition from informal conversation to the study interview. The participants were encouraged to ask questions and raise concerns before final permission was sought to start recording, which was the prompt for me to switch the recorder on, and to remind participants that they were the experts of their caregiving experience and that there were no right or wrong responses or disclosures. The participants, once they became comfortable with the recorder, were overall quite at ease with the process and spoke freely as they described their caregiving experiences.

3.4.2.7 Closing the interviews

Interviews were closed with thanking participants for their time and contribution. After stopping the recorder, time was spent discussing social issues, and taking up the offer of sharing a cup of tea, which I knew culturally to not accept would seem disrespectful. It also served not only as a further means of building rapport, but also ensured participants were not left distressed following the interview. I was mindful of the notion of 'taking the data and running' (Clarke and Keady 2002), and as participants had given me their time, I felt obligated to not to leave immediately. My contact information was made available as needed, for further support or advice.

3.4.2.8 Transcribing the interviews

After each interview, brief reflexive impressions were noted immediately to later facilitate immersion in the data. During the process of listening, thoughts, ideas, and reactions related to the recording were noted, and this written text, together with the sound recordings, personal notes and theoretical notes, constituted the material for analysis. Recordings were transferred from the audio recorder and uploaded to a file on the University's secure server which could only be accessed by me. The audio recording was then deleted from the recorder. I chose to personally transcribe all the recordings as the interviews had nuances and words that, as a Jamaican speaker, I was able to understand more readily than they might have been if transcribed by someone else. To seek clarity regarding bias, as part of this process the transcripts were anonymised, and identifying information removed.

3.4.3 Qualitative Analysis of interview data

Data analysis is a complex term contested by some qualitative researchers (Creswell 2013), nevertheless some features of the process are prevalent namely organising the data using a method of coding, then reducing this data into themes, and presenting these themes in a discussion (Creswell 2013, Grbich 2013).

3.4.3.1 Trustworthiness of the data

Trustworthiness is the most important aspect of any data analysis. According to Moule (2014), trustworthiness is about demonstrating plausibility, credibility and integrity in the process and as Polit and Beck (2012) state, trustworthiness within any study is best demonstrated by outlining a clear process (with examples) of how the analysis was conducted. Silverman (2011) argues that although interviews are recorded and may be transcribed verbatim, the issue of interpretation by the researcher may be questioned, since qualitative studies provide readers with only brief data extracts, which may not provide a true perspective of the participants. Morse et al. (2002:14) argue that qualitative researchers should implement 'verification strategies' throughout the conduct of their study, rather than when the study is completed to ensure attainment of rigour. Verification strategies advised by Creswell (2013) were considered and applied: Peer review using Action Learning Sets with a cohort of colleagues undertaking Professional Doctorate study and a research diary was kept throughout the research process recording reflexive thoughts. By continually questioning ideas and motives while collecting data, I was able to acknowledge any possible preconceptions or bias. The final factor was the adoption of an honest and transparent approach through all stages of the research study as an insider/outsider researcher who was part of the community I was

researching. Within this study, to address any concerns about trustworthiness I have documented and illustrated the process at all stages and used the words of the participants to generate the themes and subthemes which were critically reviewed by my academic supervisors. Based on these discussions some changes were made to the themes in terms of groupings and labelling.

3.4.3.2 Framework and process of analysis

The literature on phenomenology does not define a single method for working with interview data. Instead, researchers are encouraged to be innovative in how they approach analysis (Creswell 2013), always keeping in mind, however, that the fundamental principle of the phenomenological interview is that the research must remain true to the data. (Grbich 2013). Thematic Analysis (TA) (Braun and Clarke 2006) and Interpretive Phenomenological Analysis (IPA) (Smith et al. 2009), popular strategies for phenomenological studies, were explored. Experiential TA (Braun and Clarke 2006) specifically, was chosen as it focuses firmly on the participant's standpoint - how they experience and make sense of the world, as opposed to Theoretical TA which is guided by an existing theory, or Inductive TA which aims to generate an analysis from the bottom (of the data) up; and although analysis is not shaped by existing theory, it is always shaped to some extent by the researcher's standpoint. The main weakness of IPA for this study was that the role of the social-cultural context is often unclear (Larkin et al. 2006).

The process of qualitative data analysis is an iterative or recursive one, involving becoming familiar with the data through moving backwards and forwards across it, reading, and re-reading until confident of what it contains. To allow the reader to

assess whether the findings of this study are adequately supported by the data, the framework used (Braun and Clarke 2006) is shown on Table 3:1 below and the steps reported in detail.

Phase	Description of the process
Familiarising oneself with the data	Listening. Transcribing. Reading and re-reading, noting down initial thoughts and ideas
Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing the themes	Checking the themes work in relation to the coded extracts (level 1) and the entire data set (level 2) generating a thematic map of the analysis)
Defining and names themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and naming each theme
Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract samples, final analysis of selected extracts, relating back to the research question and literature, producing a scholarly report of the analysis.

Table 3:1 Phases of Thematic Analysis (Braun and Clark 2006:87)

3.4.3.3 Familiarisation

The interviews gave the participants an opportunity to tell their stories which became data for the study. For the data analysis to be effective within a phenomenological study the data needs to retell the story in such a way that it is understandable to the reader. Creswell (2013) writes that analysis begins during the interviews, as the researcher actively listens and consciously thinks about what is being said. Familiarisation is not a passive process of just understanding the words of a

transcript, it is about starting to 'read data as data' (Braun and Clarke 2013:205), actively, analytically and critically. In Experiential TA these notes may become the initial building blocks in the process of coding and building final themes, in contrast for example with IPA where the focus is on capturing and interpreting the participants experiences then putting them aside for a while so that researcher remains focussed on the participants meanings and experiences.

Audio recordings were listened to within 24 hours to review each interview, with notes written to capture general observations, impressions or ideas. Each interview was transcribed verbatim (Appendix 3:236), and loaded onto NVivo 9 so that transcripts could be read with the audio recording running alongside to ensure that transcripts were accurate. During this process, anything of interest was noted. This phase is described by Braun and Clarke (2013:205) as observational and casual rather than systematic and precise, with notes written down as a stream of consciousness, 'a messy rush of ideas' rather than polished prose.

3.4.3.4 Generating initial themes by coding

Coding is a process of identifying aspects of the data and relating it to the research question. A code is a word or a brief phrase that captures the essence of why a particular part of the data appeared relevant to the research question. Data derived codes provide a succinct summary of the explicit content of the data; they are semantic codes (Braun and Clarke 2006), because they are based on the semantic meaning in the data and should mirror participants language and concepts. Initial notes were made on each transcript of anything that was of interest; the specific way that each participant had responded; pauses; words used; mood; stress; distress; etc. and these were coded using 'complete coding' (Braun and Clarke 2006:82).

Complete coding is the is the process of exploring whatever possibilities present in the data, anything and everything of interest or relevance to addressing the research question. The method I used was to apply codes to the transcripts using *the participants' words.* Using these recurring words, the scripts were examined for similarities and divergence.

Nvivo is one of a range of programmes available to code and conceptually map data to explore relationships between codes (Bazeley & Jackson 2013). As key words or statements began to be identified using NVivo 9, these codes were grouped under parent codes and created a list of 50 codes. However, following a catastrophic crash of my research laptop which was the only computer onto which NVivo 9 was loaded, and then being advised after several weeks that the coding data was not recoverable after re-imaging with NVivo 10, I decided to review the transcripts manually. A line-by-line study of every part of the data text, was done. As key words or statements began to be identified, clusters were formed using different coloured post-it® notes on sheets of flip chart paper, similar to a process described by Moule (2008). This process was laborious and messy (Appendix 3:237), and I was overwhelmed at times as the data did not always fall into neat categories and there were many ways of linking different parts of each interview and observations. But I experienced a feeling of the richness of the data in a different way to the work previously completed on NVivo.

3.4.4.5 From codes to themes

Questions to ask when developing themes

- Is this a theme (is it just a code or a subtheme?)
- Is there a central organising concept that unifies the data extracts?
- What is the quality of this theme? Does the central organising concept tell me something meaningful about the pattern in the data, in relation to my research question?
- Can I identify the boundaries of this theme? What does it include and exclude?
- Are there enough meaningful data to support this theme? Is the theme too thin?
- Is there too much going on in the theme so that it lacks coherence? Are the data too diverse and wide-ranging? Would using subthemes solve this problem? Or should it be better split into two or more themes, each with its own central organising concept?
- How does this (potential) theme relate to other (potential) themes? Is the relationship between (potential) themes hierarchical or linear?
- What is the overall story of my analysis? How does this theme contribute to that overall story?
- Is the central organising concept reflected in the title that I have given to the theme?

Figure 3:1 Questions to develop codes to themes (Braun and Clarke 2013:226)

Using questions developed by Braun and Clarke (2013:226) similar descriptions of experiences across the data set were put into clusters, again using the participants' words to ensure they reflected what the participant originally described. I searched for relationships between these themes by creating a diagram with the heading 'the essences of caregiving' and made more notes. Qualitative theme development cannot be determined in a quantitative way, (Buetow 2010). Determining the importance of a theme is not just about counting (e.g. frequency overall, or frequency within each data set) it is about determining whether this pattern presents something meaningful and important in addressing the research question. (Braun & Clarke

2006). Themes presented in final report may not necessarily be the most common ones, it is about telling a particular story about the data, that addresses the research question. It is not to present everything that was said in the data (Braun & Clarke 2013). Qualitative research is not about finding the right answer, it is the best 'fit' (Braun & Clarke 2013:230) of analysis to address the research question.

Countless weeks of reflection and re-examination ensued, together with an intense session of critical reflection with my supervisors that challenged and helped the formulation of my thinking as the data was grouped and re-grouped under overarching themes to enable the phenomenological essences to be identified, (Appendix 3:237).

3.4.3.6 Reviewing and naming themes

As stated before, qualitative data analysis is not a linear process. It is recursive. The object of naming themes is to determine if the themes fit with the coded data and whether someone reading the analysis and the data set would recognise that fit (Braun & Clarke 2013). Lists of related quotes were brought together and interrogated to develop a set of distinctive coherent themes and a sense of how they fit together and the overall story that they tell in the data. The overarching themes developed and the subthemes which helped to capture and inform each theme, were noted by initially choosing short excerpts from the data (Table 3:2) below.

Theme	Informed by:
Strength and resilience	"Jamaicans are strong" **"**a strong woman who lived life on her own terms" "a hardworking woman" "Mom was a strong proud woman of God" "I'll just do what I need to do for however long I need to do it" "We educated and have big job … but only God will keep us"
A labour of love	"I do everything" Manage incontinence Deal with parent hoarding rubbish Going out and getting lost "Have to protect them… you know people take advantage even stealing money if they see them out at the bank or shopping" "Husband, children, job responsibilities … lots of juggling" "just adapt to a new lifestyle"
Picking sense out of nonsense	"GP/Primary physician not helpful at all" "No information" "Not referred to any specialist" "finding out there is no cure" "Word of mouth - called ……. for help" "Only other families in same situation really want to talk and even begin to understand"
I'm not a carer – I'm family	"I'm not a carer- this is my Mom" "If not me, then who?" "Once a man twice a child… that's how life goes isn't it …same way we need someone to protect and care for us at the start, same way when we get old" "I'm now the family heartbeat" "… family …everyone tries to do their part to help"
"**Jamaicans don't do that**	Unconscionable "What would that say about us as Black people?" "…'let down my parents" "Would not trust them not to ill-treat my parent" "Over-reliant on medication" "Only if/when physical care needs overwhelming"
The Church needs to do more	"'Disappointed with church support" "Church does not appear interested" " Church should be offering financial help after years of tithes and offerings" "… need to harness that energy and influence to educate and advise"

Table 3:2 Overview of Themes Source: Author (2015)

3.4.3.7 The experience of analysis

Although outlined as a step-by-step approach, the analysis was by no means a straightforward and linear process as presented. What was learnt during this process was that qualitative research is a discovery-orientated method of research that cannot really be reduced to a particular set of steps, despite its stringent observance of principles designed to facilitate the articulation of strong, evocative, auditable and authentic accounts of phenomenological experience (van Manen 2005). Phenomenology is concerned with human experience as it is lived. Its focus is on revealing details, sometimes seemingly unimportant, with the goal being to achieve understanding. Heidegger (1927/2011) writes that the ordinary lived experience, tends to become quite extraordinary when examined with a phenomenological gaze, but In order to conduct a phenomenological study, the researcher must have experienced the phenomenon in order to research the phenomenon (Laverty 2003). In seeking an understanding of the experience of these caregivers, my experiences as a woman of Jamaican heritage, and a caregiver for a family member with dementia were a vehicle by which meaning was assigned to the experiences as described by Littlejohn & Foss (2011), as phenomenology looks at all the descriptive texts including the researchers own experiences as equally trustworthy in the interpretation of the data.

However, phenomenology is difficult because, as a methodology for analysis, it is difficult to get it right. The phenomenological view of experience is complex (Smith et al. 2009), and when one is new to phenomenology as a method of analysis in qualitative research, it is easy to make mistakes in identifying experiences (or, as described here, isolating themes) and it is difficult to know that one got it right – that

one has extracted and defined the meaning of the participant's experience. Also, the use of language and the interpretation of a person's 'meaning-making', their attribution of meaning to phenomena, is central to Heideggerian phenomenology (Smith et al. 2009). Again, this is the interpretive part of 'interpretive phenomenology'. I have therefore been careful to maintain the integrity of the participants' telling of their experiences in the analysis and not allow any interpretation influenced by my understanding of the participants' use of the Jamaican language, particularly when having to make some minor adjustments to enhance readability.

3.4.3.8 Producing the report

Presenting the findings of a qualitative research project is an important and difficult task that appears to generate much discussion, (Reay et al. 2019). Reay et al. (2019) concentrated on this critical issue and tried to shed light on how a sample of published studies presented their research outputs. Their study elaborated five major approaches used by researchers. The first is called the Gioia approach (p206), in which a theoretical coding structure is used to organise text. A chart illustrates coding information, and data tables are organised by coding structure. Finally, the snippets of text are provided in this approach, and interviews and archival data are used as the primary sources of data. The second approach is the Vignettes approach (p207), where short stories are derived from data. Usually, ethnographic data are the primary data sources in this approach. The third approach is called Temporal Phases (p208). Here, the text is organised to present a story that unfolds over time. Interviews, archival data and ethnographic data are used in this approach. Long Data Excerpts is the fourth approach (p209), and involves the use of interview

transcripts, which are shown in segments. Lastly, there is the Anthropological approach (p211) in which overall research context is emphasised in the text. This approach provides a comprehensive understanding of the phenomena of interest. Ethnographic data are the primary data sources used in this approach.

Each of the approaches described has its advantages and disadvantages, which Reay et al. (2019) advises should be considered before settling on one, and also during the process of presentation of the findings. It should be noted that these approaches have similarities as well as differences, which makes it possible for creative researchers to choose the best approaches in order to present their findings.

With that in mind, I have therefore chosen to use a modified Long Data Excepts Approach as described by Reay et al. (2019). Rather than presenting a theoretical narrative in which data serves to support the identification of theoretical concepts, the long data excerpts approach, as described by Reay et al. (2019), organises findings around the raw data, which fits with the phenomenological approach of this study, where the narrative is used as a vehicle for understanding the cultural and historical context in which the lived experiences is being told, (Bernard & Ryan 2010). By presenting data in an unfiltered way, the researcher attempts to respect the integrity of the original exchange (Reay et al. 2019). Using excerpts of the participants 'interview transcripts allows the reader to make some assessment of their validity through personally evaluating how the themes identified are grounded in the data. The long data excerpts approach is a particularly effective way to capture data in its full richness. One of the advantages of this approach is that it preserves

the emic nature of the research, but there can be a difficult 'trade-off '(Reay et al. 2019:210) between breadth and depth, as this approach relies on the presentation of a relatively small number of specific episodes that researchers claim are representative of issues. I would argue that use of data excerpts does not always require large chunks of data to capture the overall story. An example to support this view is in Theme 5 of my study, where there was a repetition of the same one word 'unconscionable' from several participants as an immediate response to the question regarding the placement of their relative in a long-term care facility. Did this require a long data excerpt to relay the story or did, as I believe, that one word on its own portray the sentiment? Creswell (2013) asserts that phenomenological research attracts and encourages the genuine essence of human experience as is it experienced by the individual. Through phenomenology the research can identify key emotions, thoughts, and feelings. The concept is to allow individuals to present how they perceive, describe, feel, remember, understand and refer to an experience. (Patton 2002).

3.4.3.9 Towards a reflective account

In this section I provide a reflexive account, asking myself how who I am may have influenced the research. A reflexive approach accepts that although the researcher does not take centre stage in the research they are, inescapably, a central figure who influences the collection, selection and interpretation of the data (Finlay and Gough 2003). Reflexivity involves researchers critically reflecting on their own preconceptions and monitoring their relationships with participants and their own reactions to participants' accounts and actions (Holloway and Wheeler 2002).

Taking a critically reflexive approach can reveal that more is at stake than an "ephemeral ideal of philosophical purity" (Thompson 2002:143).

The term insider research is used to describe research where the researcher has experience of, or a connection with, the research setting (Robson 2002). I realised issues relating to 'insider' and 'outsider' positions (Heugten 2004:210) reverberated throughout the participants' narrated experiences and my own.

Researchers who are insiders of a setting studied are likely to have their own perspective and interpretive standpoints which may differ from those of outside researchers, as discussed by Serrant-Green (2002). The difference in these perspectives can have implications for the nature of the knowledge produced in the course of the research. For example, I had to consider the potential impact of my nursing experience, knowledge of dementia, and experience of caregiving on my interpretive decisions and conclusions. Nevertheless, there are compensating advantages of insider research, such as having a wealth of knowledge that the outsider is not privy to, and the fact that familiarity may mean participants are more open in their responses (Heugten 2004). Nevertheless, it has been suggested that the concept of trustworthiness becomes increasingly problematic for the insider researcher because of their involvement with the subject of study (Kvale and Brinkmann 2009). I attempted to minimise the risk of compromising the study by acknowledging my subjectivity as an experienced nurse and as a woman of Jamaican heritage, at the same time emphasising my impartiality seeking to be open and honest within the research process. I acknowledged that I was the main instrument in deciding the analytical approach, and the aspects of the data to be included and excluded in the report. However, I ensured that the voice of the participants and the illumination of the phenomenon under study had priority.

I was aware of the purpose of reflexivity in the research process, yet in the early days of this study I grappled with the concept. I struggled to understand how my subjective thoughts, feelings and experiences could have such an impact on the research data and analysis. I was soon persuaded that epistemological positions, although personal and subjective, influence how we conduct and interpret research. Examining my epistemological position has assisted me in clarifying my views and the ways in which I interpret research, and in doing so helped to explicate my views and opinions on truth, knowledge and reality. I embrace the fact that epistemologies are central to the production and consumption of health research and that engaging with epistemology is integral to learning the craft of research and helps me to shape my abilities and appreciate the research of others. As a nurse, I have a responsibility to make a continued contribution to research and recognise the importance of practitioner research and the application of research-based knowledge to develop and support high-quality care.

In terms of this study, I viewed my position as that of a researcher and believed that I should be able to engage with the issues as perceived and experienced by others. Initially, my familiarity with the challenges of the participants' experiences placed me at a disadvantage. There were moments throughout the study when I had to remind myself that I was in a researcher's role. It was important for me, through reflexivity, to try to be vigilant of the fact that my insider knowledge and position as a nurse could affect the stages of the research process. I was also mindful that this was my first attempt at conducting qualitative research. I had previously only conducted quantitative research. Critically reflexive insights provide a means for better enabling researchers to think outside their usual paradigmatic and disciplinary boxes,

(Zaltman 2000). My response to being a neophyte in this field was to position myself as a learner.

Phenomenological approaches are good at bringing deep issues to the surface and making voices heard. When I compared my first interview to my final interview, there was a marked improvement in the way the interviews flowed as I accepted the silences and allowed participants time to express their thoughts.

Data interpretation was extremely intellectually challenging as I had in excess of 300 pages of interview data, an enormous volume, and soon realised I would not be able to use all that had been collected. This meant I spent a lot of time deliberating on what should be excluded. Following discussion with my supervisors, I was able to come to terms with decisions made, knowing that excluded data could always be further explored in the future.

Humphrey (2007) concluded that to produce a full account of her research she had to write about the way it had caused her to re-evaluate her own identity, because she discovered that the truth of self is integral to the truth of a study. For me, this made sense, as I had to appreciate that I had to be able to recognise what was happening to me in the course of the research and to able to give an authentic account. My contribution lies in my ability to reveal the richness, depth and complexity of dementia caregiving in Jamaican families in England and Jamaica.

3.5 Chapter summary

This chapter has discussed the methodology and the research methods underpinning this study. Participant recruitment, ethical considerations, data management and data analysis were presented. Strategies for ensuring trustworthiness focused on verification strategies used to establish the credibility of the research findings. Also included, a discussion of how the findings will be presented using the Data Excerpts Approach (Reay et al. 2019). The chapter closed with a detailed reflexive account and insider/outsider perspectives.

I am confident that the findings presented in the next chapter are supported and justified by the data.

Chapter 4 Findings

4.1 Introduction

This chapter presents the findings from the thematic analysis of the interview transcripts and discusses the identified themes using Braun and Clarke's (2006) six-phase thematic analysis framework as discussed in Chapter 3. (Figure 3.1). I engaged in an iterative and reflexive reading of the transcripts that enabled me to examine the salient features of the participants experiences as they related to the research question namely, What is the lived experience of dementia caregiving by women of Jamaican heritage?

The findings from the analysis of interview transcripts are presented under six themes, developed from phrases or statements used by the participant caregivers. The identified themes are (1) Strength and resilience; (2) A labour of love; (3) Picking sense out of nonsense; (4) I'm not a carer – I'm family; (5) Jamaicans don't do that and (6) the Church needs to do more. Themes and discussion are presented sequentially using the Long Data Excerpts Approach (Reay et. al. 2019), (modified as outlined in the previous chapter), to allow the reader to make some assessment of the validity of the discussion through personally evaluating how the themes identified are grounded in the data.

4.2 Participants

A total of 10 participants took part in the study. (See Table 4:1 below).

	Gender	Age	Relationship to person living with dementia	Relationship to caregiver	Location of interview	Caring for how long
P1	Female	50s	Daughter	Mother	UK	5 years
P2	Female	50s	Daughter	Mother	UK	4 years
P3	Female	50s	Daughter	Mother	UK	5 years
P4	Female	40s	Daughter	Mother	JA	6 years
P5	Female	50s	Daughter	Mother Father	UK UK	6 years 4 years
P6	Female	50s	Daughter	Mother	JA	7 years
P7	Female	50s	Daughter	Mother	JA	5 years
P8	Female	50s	Niece	Aunt	JA	5 years
P9	Female	50s	Daughter	Mother	JA	15 years
P10	Female	60s	Sister	Brother	JA	4 years

Table 4:1 Study Participants: General Information

All participants were first-generation children born to Jamaican parents who had migrated to England, Canada or the US from Jamaica during the 1950s and the 1960s. The participants in England had limited experience of growing up with, or caring for, older family members.

> *… the realisation that we are the first generation of children here caring for parents, and it's basically learning as we're going along… I've become a parent to my parents, and I am still a parent too*
>
> *P5: lines 165-170*

> *The strange thing is they looked after their siblings but not their parents because they came to England, they sent clothes, food, money for doctors' bills but they didn't get to care for them, we didn't get to care for our grandparents that's the difference for my children …. Mom living with us… hoping it will make them more compassionate when my time comes… and not just chuck me in a home somewhere like how the English do*
>
> *P3: lines 70-75*

All the participants were women. Eight were daughters of those they were caring for, one a niece and one a sister. The literature shows that the responsibility for caregiving within BAME communities falls predominantly on female caregivers (Ho et al. 2003; Adamson & Donovan 2005; Jutlla 2011 & Botsford et al. 2011) and this study supports that. Eight of the ten caregivers identified as 'daughter' and held strongly to that familial identity (further elaborated in theme 4 – I'm not a carer – I'm family), not liking to label themselves as caregivers.

Half of the participating group (5) were educated to university level, while the other half did not extend their education beyond further education college level. Nine participants were in paid employment for a minimum of 15 hours each week. All recipients of care were Jamaican-born. As noted by White (2006), the world they lived in at the time of the study was not one they had envisaged for their senior years. Many had anticipated retiring back to Jamaica, but only two of the care recipients had done so.

> … we only planned to be here for five years … how many times did we hear that growing up?
>
> P4: lines 39-40

The care recipients presented as strong, proud, women, who had invested heavily in bringing up their families amid the challenges of settling in a new country.

> *…Mommy was strong…she went to live in America, worked as a Nurses Aid…ten years... she just worked and worked and then she bought her house back in Kingston in cash… she was a strong and determined woman. She brought us to England for better opportunities and worked and worked to give us the chance to do well. I'm proud of mommy, and I know she's proud of us …*
>
> P4: lines 79-83

> *…Mom was a strong proud woman of God…she came to England already qualified as a teacher and discovered that they wanted her to train again, which was almost impossible at that time, but she worked very hard using those skills in other ways, she taught at Saturday*

School, and Sunday School… she wanted the best for us

P2: line 15-19

…Mom was a strong Jamaican woman who lived life on her own terms…She came here as a single woman… not sure I would have had that kind of courage...

P5: line 27 -28

While there is a lack of research into the caregiving role of men in relation to culture and ethnic background (Houde 2001), this study, like research into African American caregivers (Cloutterbuck & Mahoney 2003), found that the majority of caregivers were daughters or daughters-in-law, and that care was shared within a family network in which caregiving was seen as something to be provided by a range of relatives, (further elaborated in Theme 4). However, Kwok (2006) showed that sons were often only able to take on the role of caregiver because of the contribution of their wives, further highlighting the complexity of gender divisions of work within BAME families.

4.3 Themes

4.3.1 Theme 1 Strength and resilience

The first theme captured shows the participants as strong resilient women doing their best to cope in the face of new challenges. Their narratives described Jamaicans as proud people whose identity is associated with strength. There was an overwhelming sense that cultural identity impacted positively and although the participants were born in different countries across the Diaspora what they had in common was pride in being a Jamaican. Participants spoke about the lives of their family members, experiences of migration from Jamaica, and the way Jamaicans

worked together in those early years to overcome some of the most difficult early migration experiences.

> *… Jamaicans, we strong… we have to be…* *P3: line 44*

> *…consider how hard our parents had it when we were small, they couldn't buy houses in certain areas, couldn't get jobs they were more than qualified to do, even the churches wouldn't extend any kind of welcome to them to attend…God bless pardner[8] draw… they humble themselves… rent rooms and shared houses and buil[9] up their churches … when them want to put us to the bottom of the class in school… they sent us to Saturday school, and VBS[10] … we know we are what we are today because of their strength…*
>
> *P1: lines 37-45*

On the part of the participants in this study, there was a striving to demonstrate a strength similar to that shown by the older generation and to achieve and succeed as their elders had done and this influenced their optimism about whatever challenges lay ahead regarding their caregiving responsibilities. Jutlla and Moreland (2009) emphasised that an important starting point in achieving person-centred dementia services is the need to pay greater attention to the diversity and complexity of families living with dementia. This is because the way people have structured their lives and identities will influence how they experience and cope with dementia. Laverty (2003) states that a person's culture, what is given from birth and what is handed down, presents them with ways of understanding the world. A person's background and culture constantly influence their responses, which means that nothing can be encountered without reference to it. Therefore, as noted by Downs

[8] A pardner is basically a partnership among people to save collectively. The "pardner" has been popular among Caribbeans in the UK since they started arriving in England and discovered credit services from banks were not easy to come by. It engendered a good savings discipline and allowed many to save to buy homes and cars.
[9] built
[10] Vacation Bible School. A Summer camp activity organised by the Church.

(2000), the influence of cultural factors must be considered when trying to understand the lived experience of caregivers.

A strong faith in God, with examples of survival and adaptation displayed by the person they were caring for, was both a motivating factor and also a major resource for participants on their own journey. I sensed that participants expressed their belief in God by more than church attendance. For them, prayer was a way of life. It was a source of strength and, consequently, provided them with a coping mechanism. Participants talked of the role of their faith in accepting dementia in the family. Although prayer was very much part of their daily toolkit for coping, this did not prevent them seeking or accessing help when it was needed. Participants talked about their memories and their understanding of the difficulties witnessed while growing up, making special mention of the role that their faith, church, and access to church for schooling and socialising had played in building a spiritual and emotional robustness and a powerful will to survive in the harshest of circumstances.

The church had been a source of strength and remained an important part of their lives, providing a sense of community and cohesion. Participants explained how the church was also key to maintaining friendships and getting support in their day-to-day lives, especially when caregiving responsibilities felt overwhelming.

> *…It's nice that people care and keep in touch…the bredrin[11] they phone and write, and sometimes they visit, but mainly if Daddy is in the hospital… some of them seem upset when Daddy doesn't know who they are and don't really know what to say…Pastor is wonderful, not a week goes by when he doesn't call or sends a little message. He comes to the house and does communion…things like that mean so much, so so much ….*
>
> *P5: lines 377-383*

[11] Bredrin – subdialect for the word brethren meaning friends in the context of church friends

There were also several commonalities in the narratives that indicated that strength and confidence to cope with caring were also influenced by generational status, education and material circumstances,

> *...look how far we reach, how much we have achieved …we educated and have big job …we mus' can cope*
>
> *P1: lines 61-63*

> *…I was a lawyer in the US before coming back to Jamaica to look after my Aunt…I have to believe I have the skills, if I could just get the information…*
>
> *P8: lines 428-430*

> *… I am a laywer here in Jamaica supporting the rights and welfare of women across the island, … this dementia is a real challenge, but my mother worked incredibly hard in Canada to get me this far… I have to make her senior years better than this…family is always more important.*
>
> *P9: Lines 220-223*

Participants stated how their education and professional acumen had enabled them to develop and utilise significant cultural and social capital to negotiate the challenges of simultaneously maintaining careers, marriages, caring for children, and caring for elders. Participants' descriptions of drawing strength from various sources in order to remain positive are echoed in the literature, drawing from past challenges (Shim et al. 2013), and drawing from faith (Duggerley et al. 2009). This capital appeared to come from families, the church and the wider Jamaican community within their home countries and abroad, with narratives constantly alluding to the solid foundation set by their parents' hard work and how that was enabling them to cope and care for them now with respect, dignity and love. Of note, Sanders & Adams (2005) reported that caregivers who struggled to report any gains in their caregiving experiences were most likely to be caring in isolation, a factor that is not so evident within Jamaican communities.

Much of the research on family caregivers has been grounded in forms of coping models (Lazarus & Folkman 1984; Schulz & Martire 2004; Pinquart & Sorenson 2005). What the participants in this study revealed was that while individual strengths developed, cultural values also strongly influenced the process of coping. The sense of having parents with solid connections to Jamaica seemed to foster a strong cultural identity in all the caregivers.

Research on Caribbean families has described their parenting style as strict, with high expectations of manners, respect, and hard work, as well as educational achievement and social competence (Griffith & Grolnick 2013). This study suggests that there is a connection between how the participants were raised and how they coped with the challenges of caregiving, including the strategies they adopted in seeking support and information. In common with several previous findings (Lampley-Dallas et al. 2001 Cox 2007 Botsford et al. 2011 & Valdez et al. 2013) this study suggests resilience is demonstrated by the participants' deep capacity for hard work and the sense of needing to adapt in order to cope with challenges instilled in them since childhood.

Various processes may encompass resilience, writes Gaugler et al. (2007), positive outcomes despite negative circumstances ("resilience as *overcoming the odds*"); sustained competence or positive development while experiencing continual threat or stress ("resilience as *stress resistance*"); and recovery from negative life experience or trauma ("resilience as *recovery).* Resilience, as conceptualised, in this study, is 'stress resistance' to the demands of the caregiving role. Windle's (2011:163) theoretical framework helps an understanding of the factors that impact on resilience building, by defining resilience as '*the process of effectively negotiating,*

adapting to, or managing significant sources of stress or trauma. It is about how the participants cope through the various stages of pre and post diagnosis in the face of adversity.' Windle's theoretical exploration of the concept of resilience highlights the degree to which resilience is interlaced with everyday life. As with the factors that impact on the ability to be resilient demonstrated by Windle, the participants in this study, in facing their daily challenges, developed the ability to manage the effects of adversity through the example of family support previously received from their relative, and their continued belief in God, resulting in positive adaptation. Consistent with this finding, Bailey et al. (2013) suggested that resilience for coping with dementia, can encompass the ability to continue with established roles, that (re)affirm a sense of self and build on a lifelong accumulation of social, knowledge, psychological, and material assets. The importance of this is demonstrated by participants who related that their educational background enabled them to develop and call upon significant cultural and social capital to negotiate the challenges of maintaining careers and marriages and caring for children and elders simultaneously.

This capital came from within their families and churches, and the wider Jamaican community in both their home country and abroad. Such network-supported resilience among families and communities' echoes research into African American communities in the US (Knight & McCallum 1998; Haley et al. 2004). These studies argue that African Americans tend to show a significantly greater ability than other groups to manage the emotional and physical demands of caregiving and to protect themselves from its negative consequences. These caregivers were less likely to view caregiving as intrusive and more likely to hold positive views about the obligation to care while retaining their sense of self. Haley et al. (2004) argue that

the process of adaption to long-term oppression, segregation and socio-economic deprivation has resulted in the capacity to 'reframe' difficult life experiences. This capacity allows African Americans to deal more effectively with the demands of caregiving. The participants in this current study presented their 'Jamaica-ness', a stoic ethnic and cultural identity as Jamaicans, in similar ways, showing it to be a powerful and positive influence on their capacity to cope. For them, it linked their individual, family, and national identities with strength, resilience and the will to survive all challenges, regardless of whether the caregiver was caring in England, or Jamaica.

4.3.2 Theme 2 A labour of love

This theme was captured through the thoughts and feelings described when participants were prompted to discuss what their day-to-day experiences of caregiving were like.

> *…I do everything…* *P2: line 59*

> *… found out people would take advantage even stealing money if dem[12] see Mommy out at the bank or shopping… so I had to start going everywhere with her to pay bills and get food…*
> *P4: lines103 -105*

> *…if you distract for a minute, Mommy turn through the door and the next minute she laas[13], the worry is immense…*
> *P7: lines 117-118*

Participants spoke about taking on increasing responsibilities beyond maintaining the safety and well-being of their parent, including needing to provide physical care such as washing and dressing, and balancing this with maintaining privacy and dignity.

[12] They. Jamaican subdialect - plural for any number of persons more than one
[13] gets lost

…Mom who was always elegant and so softly spoken, now just getting her to bade[14] is like tearing down the place…

P9: lines 94-97

…Daddy, him so distressed when him mess his clothes, either with food or not getting to the toilet faas[15] enough… I lose track of how many times a day I have to help him put on clean clothes…

P5: lines 222 – 224

…any decision about the house, it's me, sorting the bills, it's me, I play a big role… I don't mind because I am the eldest girl … mommy's safety is paramount… she knows to lock the grilles; she's even locked me out… it is a real labour of love that's all I can say…

P4: lines 137-140

This theme also revealed that, in spite of the sometimes very challenging situations in managing the changed personality and behaviours of their relative, there was a willingness to fulfil the expectation that family members would be cared for at home, even if residential care facilities might have been available. This wanting to care at home did not appear to be linked to any feelings of guilt but rather to a desire to maintain the dignity of their family member.

…anything, anything, if it meant my mom did not have to go into a home... my worst nightmare was the thought of putting her in a home. I was doing everything possible… I would do anything possible for as long as possible for that not to happen...

P1: lines108-110

…most of these so-called homes are run as a business no caring going on in them at all…food that can't eat…and a whole heap of different people dealing with intimate hygiene needs… no, no, no not my mother… I prefah dead[16] first…

P5: lines 279-281

…Some family said I should take her back to England so she can go to a day centre or something like that but she benefits from the sunshine,

[14] have a bath
[15] quickly
[16] would rather die

> *she benefits from walking around her own yaad[17] in her own perimeter, what would she do sitting by a window all day, sitting in a circle with people she doesn't know, Yuh mad. No... culturally… the food…No. I would give up work to ensure that never happen…*
>
> *P4: lines*

Several participants spoke movingly about sometimes feeling isolated from support that may be available because they could not bear for their family member to be seen in a very frail state, especially given their previous sense of pride and independence. For example, one reason given for church attendance becoming less regular was that, despite experiencing feelings of estrangement, they desperately needed to maintain their family member's dignity, especially as the dementia worsened with accompanying incoherent speech, restlessness or wandering behaviour, the inability to express their needs or ask for help, and incontinence.

> *… it is a huge sadness to not be able to take my mother to church regularly… still she wouldn't want to be seen so frail... I have to respect that but it's a lot to bear at times….*
>
> *P2: lines 305-307*

Some participants in England reflected that caring was constant - all day, every day - as they did not access support groups or services, even though this had the result that they were probably seen to be coping better than was actually the case. They also stated that when they had ventured to accept outside support, these services were to varying degrees unwelcoming, culturally inappropriate, or not really helpful or respectful of the elder.

> *…it's on ongoing labour of love…I know that with white people they'll go into day care centres and stuff, cos Mommy went into a place in … for a little while, and they tried to encourage Mommy but she won't go because it's mainly white people, I know there's something else in … at the African Caribbean centre but it's hard to get into, they have limited*

[17] home area, house and garden

space… Church did a wonderful special lunch a few months back, if only they could do that a little more often…

P3: lines 144-150

There was a reluctance to seek help from health services while there was family help and support available, and they were coping. The inappropriateness of some of the day centre facilities accessed in England is exemplified by these participant comments:

…taste bad food… now you tell me which Black person going to eat faggots and peas. ...Some of them do try still, but I don't know where they get those recipes from, and as for the rice and peas, (uncontrollable laughter)… and then to top it all…imagine … asking a Christian woman if she want to play bingo… these people no righted[18]*, no righted at all… Mommy is not a fussy eater, she eats what she gets, but still … not sure if they just take this for a joke or the lack of respect for older people is so great that they don't even notice when something is not appropriate…*

P7: lines 182 - 189

For some participants, this had caused life to become more isolated, with a loss of spontaneity around family time.

…I have to always make sure that I make plans well in advance so that the whole family knows what I am doing, and we don't ever let Mom be in the house on her own…it's a balancing act, do I put Mom first, my husband, the children, everything I have to organise and plan, can't just have a random day off from it all…

P2: lines 173 - 174

…I can't shut off … occasionally I can get to go to Ochi for a day, but it's a whole heap of planning and checking and securing assurances from other family, who have other family that seem not to understand that they cannot be called away for foolishness leaving mommy on her own even for what they consider to be a short time …

P4: line 165-170

[18] not displaying any common sense

Conversely, some participants felt that their relationships with other family members, particularly siblings, had improved as they communicated more often and saw each other more frequently.

> *…The situation has made us more honest with each other about what is going on in our lives and families as we support our parents and each other…*
>
> *P5: lines 650 - 652*

A constant refrain in participant responses were the words ‘a labour of love’, an acceptance that the current situation was just a phase on the journey of life, and they were going to do whatever they needed to do for however long they would need to do it to uphold the dignity of their relative.

> *…There is a dissonance and a disconnect between wanting to do my best and being able to do my best. Even with a helper it is hard…but that’s what unconditional love is …*
>
> *P9: lines 202 -203*
>
> *…how would I describe my days…this is a labour of love… so I’ll just do what I need to do for however long I need to do it.*
>
> *P5: lines 659 -660*

As discussed in the first theme, individual and community resilience are inherent coping skills for Jamaican families. Lazarus and Folkman (1984:141) define coping as: “c*onstantly changing cognitive and behaviour efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person or the community”.* The title of this study, ‘Once a man – Twice a child’ has been echoed by Jutlla and Moreland (2009) who suggest a person with dementia has the behavioural and emotional needs of a child. Kitwood (1997) argues that dementia makes it increasingly difficult for individuals to respond to social environments, to the point where they can no longer maintain their adaptive self. The physical and emotional neediness of the person being cared for was what

participants noted struggling with the most but saw caring for their relative as an act of returning previously received care from that person.

Caregivers in their fifties and sixties found themselves caring for their elders with little previous experience of living with and caring for grandparents or other elders while growing up. It has been argued (Right Care Right Here 2012) by policy-makers in England that this lack of experience might lead to fewer family caregivers being able or willing to look after elderly relatives with dementia at home, and a related increase in nursing home admissions for Jamaican elders. But Lazarus and Folkman (1984) warn against 'stage-type' models that may cause health professionals to judge and anticipate behaviour inappropriately using arbitrarily applied stages. They cite the example of the Kubler-Ross (1969) model for death and dying that encouraged health professionals to misjudge grief responses that did not match the predicted stages and sequence. Instead, taking the view that there may be different patterns of coping for different situations, rather than standard stages or a set sequence, allowing for the integrity of caregivers' experiences to be acknowledged. Gottlieb and Wolfe (2002) note the importance of recognising that coping responses need to be in play for long enough to exert meaningful consequences. It could be argued that this first-generation pattern of experience may change as families become more assimilated into the culture of their current country and lose some of their 'Jamaican-ness,' but one participant, a niece who had been brought up by her aunt stated that the strong sense of reciprocity this created now enabled her to bring her aunt back to Jamaica and care for her in return. This positivity demonstrates the difference between dementia being perceived as a drama and a tragedy, as argued by Miesen and Jones (2005), and seeing it as an

opportunity to simply adapt and redefine caregiving roles, to deliver care with respect, love and dignity in the face of huge daily challenges.

The specific challenges of certain caring tasks, such as assisting a family member with personal hygiene, came up in several interviews. As an activity of daily living Dunn et al. (2002) note that bathing creates some of the highest levels of discomfort in the lives of individuals diagnosed with dementia. Rader et al. (2006) write that older persons with dementia who need assistance with bathing often find the activity to be both physically and emotionally demanding, as do their caregivers. Their research identified several contributing factors, including pain, fatigue and weakness, confusion, anxiety resulting from being naked possibly in front of strangers, being afraid of falling, being in a noisy or unfamiliar place, and discomfort from cold or draughty bathing areas or harsh water sprays. Resonating more closely with the participants view that caregiving is a labour of love, Rader et al. (2006) suggest that bathing be considered not as a task to be performed, but rather as a human interaction.

The narratives of the challenges that surround all activities of daily living and caring, are mirrored in studies by Miesen & Jones (2005) and Lawrence et al. (2008) but the participants in this study have moved beyond caring out of a sense of duty and demonstrate deep compassion, respect and love. They are confronting their difficulties with positivity and perseverance and, when denied access to specialist services, receiving support from family and from the church.

Is this just an experience of the Windrush generation of caregivers? What behaviours will be exhibited in the future by the children and grandchildren of these current caregivers?

4.3.3 Theme 3 Picking sense out of nonsense

This theme was captured in the narratives of the British Jamaican caregivers' experiences of living amid a sophisticated 21st Century health and social care system that was seen as incapable of dealing with someone with dementia. Participants expressed bewilderment that with so much research purportedly taking place, with health professionals and support staff receiving regular specialist dementia training, and plentiful publicity about dementia-friendly services, it was still an ordeal to make a simple GP or hospital appointment.

> *…You become very skilled at picking sense out of nonsense … how is it that dementia is claimed to be a such a big concern yet the GP doesn't seem to know what to do beyond suggesting contact with a CPN to go to a memory clinic… he can't give you information but is then unwilling to help you get to someone who can…yet at every turn dementia is news…*
>
> *P1: lines 240-245*

> *…they had absolutely no clue… GP not explaining or giving any helpful information, … he suggested referral to a CPN, which confused me, my Mom was not mentally ill… he gave us leaflets, which had online information to look up about how to sort out monies, legal stuff, driving licences, wills, power of attorney, and all this before we even have a proper diagnosis!...*
>
> *P2: lines 216-221*

In line with Mahoney et al. (2005), where participants mentioned how difficult it was to bring their family members to the doctor and report their concerns, this study notes that there is a strong willingness to seek help by consulting a GP and relevant health services. What was perplexing for participants was how negative the experience of accessing and navigating a way through turned out to be. Much energy and effort were expended in getting their elders to surgeries, usually under protest, only to be disappointed with the encounter. There were reports of GPs

dismissing reported concerns as simply the usual signs of old age or believing the elders when they denied having any problems.

> *… information I was given… very little…. even when they told me she had multi-infarct dementia it was assumed I knew what that was and even when the CPN came, she told me about a website… I think there should be more information because we struggled, we really struggled as a family because she deteriorated so quickly that by the time we tried to do legal things to control her affairs it was going to cost us a lot of money and possibly going to court. … More information about how she was going to progress, medication, what they were for, she was given a lot of tablets, we just didn't know…. neither the GP or CPN or social worker gave information when they came… We were not pointed to any kind of groups; it was one of Mommy's church friends who told what she had experienced working in the hospital and pointed us to people like you …*
>
> *P3: lines185-196*

Caregivers in Jamaica expressed similar disappointment and frustration with their primary physicians.

> *…Primary Physician not helpful at all…I came back to Jamaica from the US so was not used to this type of hardship to get information for a service that was being paid for …*
>
> *P8: lines 421-423*
>
> *…My mother lives in Kingston …. And you have to tek sense out of nonsense and see things as they are … the GP was not really listening, and was not helpful at all …*
>
> *P4: lines 170-174*

Within the literature, however, Morris et al. (2010) and Eldemire-Shearer et al. (2017) highlight a need for primary physicians in Jamaica to be more aware that memory loss should not just be attributed to straightforward ageing and adopt greater use of screening tools to help indicate when further investigation is needed.

British Jamaican participants talked of not understanding why dementia was situated in mental health services and spoke of the confusion and stigma that such a link created. Nazroo (2003) has discussed how the experience of accessing primary care is compounded by anticipatory fears of discrimination and negative experiences of services and service providers. This causes participants to make choices based on balancing the need for information and support against maintaining the dignity of their elders. When prompted, however, participants in England admitted that they had not experienced any stigma from within the Jamaican community, and there was no evidence in the community of an old-fashioned attitude that saw someone with dementia as 'mad'. Although this made caregivers feel valued, they stated that only others in the same situation as caregivers living with someone with dementia appeared genuinely to understand and be open to them.

> "*only other families in the same situation really talk, and even begin to understand…*"
>
> *P6: line 328*

The narratives expressed the journey of adapting mentally from a gradual recognition that something was not quite right to finally embarking on a long, often bewildering quest to get a proper diagnosis. Participants talked of initial confusion, moving to a gradual dawning, and then an escalating need to get relevant information, resources or support.

> *…trying to get it across to the doctor that here you have someone that grow eight children, and now can't remember how to boil a kettle to make a pot of tea…this was not just about getting old.*
>
> *P6: lines 180-184*

> *…I'm not sure when exactly the reality of finding out that there was no cure for dementia really hit me. We had to beg for tests, information, referrals to a specialist. GP not helpful at all.*

P2: lines 257 -259

> *…Mom was pivotal to the house... She did all the shopping, the cooking, the runnings,... carry the children dem up and down until we come from work… she always had something she needed to be doing for church as well, now… how does someone go from that to this…sometimes she calls me the wrong name, but you know what, our parents used to do that anyway when we were small…(laugh) but still it's upsetting to feel that she has forgotten who I am,.. but I know it's the dementia…*

P1: lines 71-75

In Jamaica, with no state-funded welfare support services, participants reported considerable disparities between public and private sector healthcare. There was a general preference for private services as explained by one participant:

> *…I think it is a combination of things, maybe not so much the quality of the service, because to tell the truth, many of the doctors that work in the public clinics same one dem[19] in private practice … it's the long waiting times. If you go to the public clinics you have to be prepared to stay there, two, three, four hours. You go to the private doctor if you can afford it, to get more attention from the medical staff, and because the waiting times are shorter…..*

P10: Researcher notes

Participants in England and Jamaica focused much of their narratives on the search for resources and support from family members and from within the community. Narratives reiterated findings by Dilworth-Anderson et al. (2002) about receipt of caregiving support from the wider family and community. Participants tended to garner support from extended family or within their own community, and the church.

> *…As well as a sense of strength, there was a sense of belonging, and an openness with others who also knew the real challenges of day-to-day caring for a person living with dementia.*

[19] doctors. dem - plural for any number greater than one. (Jamaican subdialect)

P10: researcher notes

> *…Alzheimer's Jamaica have been lifesavers…but it is more than just support for each other … as Jamaicans we have a quiet strength that impels us to keep moving… it's about policy making, legacy making …*

P8: lines 421-422

This theme opens phenomenological understanding in which the caregiving relationship is complicated by a sense of being caught in a storm of conflicted experiences and conceptualisations of dementia. Like Berwald et al. (2016) findings in this study indicate that participants in both England and Jamaica did not initially think that dementia affected Black people, despite studies by Eldemire-Shearer (2008) and Waldron et al. (2015) outlining an increasing prevalence of cognitive impairment in older people in Jamaica.

Although it is well documented in the literature that dementia is associated with stigma in some BAME communities - (MacKenzie 2006, Moriarty et al. 2011, Botsford et al. 2012, Mukadam et al. 2015) - there was no evidence that it was a barrier to the initial seeking of help for the participants in this study. What was evident however was that, having come to an understanding of dementia as a disease, the discovery that dementia services are located within psychiatric services had a highly negative impact because of the longstanding fear of discrimination and aversive treatment from mental health services within Black communities (Keating and McCulloch 2002).

4.3.4 Theme 4 I'm not a carer – I'm family

This theme was captured by participants' resistance to identify with the term 'carer'. Instead, they saw their role as a wholly natural extension of their familial relationship with the care-recipient. No participant referred to themselves as a carer. They never appeared to lose the sense of who they were, or who they were caring for, as voiced by P1, P2, and P7.

I'm not a carer, this is my mom

It is worth noting here that in Jamaica care for older relatives is still legislated in the Maintenance Act (2005) (Appendix 1:181), and deemed normal expected kinship caring, and a familial duty and obligation, as noted by Adamson and Donovan (2005), and that community – non-resident and non-kinship – caring would represent a different type of involvement and experience. Participants in England and Jamaica had dutifully taken on responsibilities, in addition to managing their own homes and families, and viewed this as an extension of their relational role with the care-recipient who had previously always cared for them.

> *…Once a man twice a child … that's how life goes isn't it… same way we need someone to care for us at the start of life, same way we need someone at the ending when we get old …*
>
> *P2: lines 230-232*

Cultural norms about roles and positions in the family meant that often the responsibility and duty to care largely fell on the eldest daughter. There were narratives around the pressure to perform this role, as summed up by this participant:

> *…if not me then who? …I think it's because I'm the eldest girl it's expected that I should look after mom a lot more and take on more responsibility and personally I don't think I can do more than I'm doing at this moment … I do feel sometimes that being the eldest is a burden and sometimes I do hate being the eldest, but you know as long as I can do the best for my mom then I always will"*
>
> *P2: line 93 -100*

No matter how complex the required care became, most viewed their role simply as an expected responsibility as the one pivotal to co-ordinating and orchestrating their families. This was voiced by both P2 and P4.

> *…I'm now the family heartbeat…*

In England, no participant had become a Registered Carer, even though being ascribed that official status may have brought extra resources and benefits such as Carers Allowance.

> *…There's no one to tell you what way to go, and Jamaicans out of pride we don't ask. Apply for benefits? …That's a dilemma. Yes, we have to pay for everything and yes it can work out expensive, and yes I realise I pay my taxes, but to tek money to look after my own Mother… No, that don't seem right…can't do that, no, not doing that…everyone is helping out…we can manage…*
>
> *P3: lines 167 -175*

Participants also focused their narratives on the search for resources and support from family members and within the community. Narratives reiterated how, because of the cultural norms associated with the role of the family in caregiving, participants tended to garner support from extended family or within their own community, mainly through the support of the church. Some participants in England were offered day care support but very little offers of support for the evenings or weekends.

> *…Social Services… poppyshow[20] they really don't give much help, always somebody different on the phone. They did give us some information about day centres and I discovered one run by a lovely sister from one of our churches …. So I try it for three days a week, from ten until around half-past three. Mom goes. She appears to enjoy it, but every little thing we try to put in place to help, it was such a trial … I tried for a short while paying someone to help in the mornings when she was going to the centre, so that she would be ready when the minibus come …but they would come after eight going up to nine by which time Mommy's ready, so by the time they got here, they was nothing for them to do… yet we still had to pay them. Couple times I left them alone with Mom just to maybe finish up her breakfast and take her tablets… and then I would be sweeping up in the kitchen and find the tablets on the floor …you just give up and go back to getting the family to help because the added stress of having a stranger in the house, that you have to pay good good money to, and they are not contributing anything positive to the situation,…*
>
> *P3: lines 279-289*

Participants in Jamaica stated that they were not aware of organised social activities or centres specifically for older people and expressed a need for more places to meet in order to create opportunities for caregivers to find information and support.

So, although the term 'carer' is in widespread use, this study supports other research (Adamson 2001, Moriarty et al. 2001, Townsend and Godfrey 2001) that suggests BAME communities find it hard to relate to the term and struggle to distinguish between caregiving and normal kinship responsibilities. The failure to adopt an approach that takes account of the perspective of Jamaican caregivers only adds to further marginalisation (Milne 2003) and continues to be a contributory factor in their under-representation in local and national assessments of the prevalence of caregiving.

[20] term of ridicule for something deemed idiotic or foolish (Jamaican slang)

4.3.5 Theme 5 Jamaicans don't do that

This theme was captured by the feelings of caregivers when asked about placing their family member in a care facility (nursing home). This evoked immediate and very strong *responses.*

> *…what would that say about us as Black people? …*
>
> *P1: line 158*
>
> *... My mother?! Nah, we not doing dat … Yuh mad!*
>
> *P4: line 398*
>
> *… I would feel that I have let down my parents …*
>
> *P5: line 272*
>
> *…Unconscionable…*
>
> *P7: line 556*
>
> *…Unconscionable…*
>
> *P9: line 400*
>
> *…Unconscionable…* *P10: researchers notes*

Participants expressed feelings of hurt and disappointment at the contemplation of having to place their relative in a care facility for long-term care.

> *…Jamaicans don't do that…I never used to understand, I suppose other people and other communities putting their elders into homes and I just thought as a Black person we are better than that, so there is an element of expecting it might come but never ever wanting it to…*
>
> *P3: lines 289- 292*

> *…Canada has very advanced programmes for care, but as soon as we realised she needed more help, we knew what we had to do as family….*
>
> *P9: line 420*

Care in a nursing home was viewed negatively and many felt that they would have failed in their duty as a child concerning their relative should that come to pass. Such evaluations did not display any kind of negative attitude towards families who do make such a decision, or any censure that they are not fulfilling their role as a child, but were expressed as personal feelings of failure and being seen as not wanting to care for their relative, should they find themselves in that position.

> *…It's hard but I know they are getting the best care… they're in their own house which they've lived in for what, fifty years… if we ever had to make that decision I would find it really hard, really, really hard, because even when Daddy was in the hospital over at …, he thought he was in a home, and started crying and I had to reassure him that we wouldn't do that to him, the same for Mommy, I know I would struggle even though I know realistically we might have to … I think that would tear the family apart…*
>
> *P5: lines 276-282*

This attitude in turn impacted on the extent that participants accepted formal support from health and social care services. The one participant whose mother had been admitted to a nursing home, after a fall at home, felt bereft at the decision. Despite the fact that her mother would now require 24-hour skilled physical nursing care she felt the decision not to continue caring for her at home had been taken out of her hands. She still felt it was her duty to ensure her mother's wellbeing and did lengthy daily visits to the care facility.

> *…. Ahhh, who feels it, knows it. My mother came to live with me. The situation was taken out of my hands...It's hard every day. Really hard.*
>
> P3: lines 342-344

The migrants who came to England in the late 1950s and early 1960s were by and large young people. There were very few 'grandparents' in this early migrant population. The participants who were born in England in the 1950s, and early 1960s have grown up with few opportunities of being around older people, or witnessing parents caring for older family members. While this first-generation pattern of experience may change as families become more assimilated into British culture and lose some of their 'Jamaican-ness', none of our participants refer to themselves as a carer, indicating that the effect of Jamaican culture is still strong for this generation.

Some participants did express concern that, while they had happily welcomed parents into their homes as part of an extended living arrangement, and had many siblings to support them, they themselves had only one child, and one participant had no children. So, while intergenerational households appear to be less prevalent in Jamaican families than in earlier times (Cloos et al. 2010) it is evident that elders are not depending only on close family but also on others in an extended network. The ability to be able to draw on support from the wider community, especially the church, was very important. The positive effect noted of church attendance and having a church community was consistent with other research in similar communities, particularly research among African Americans by Holt & McClure (2006).

The Jamaican community and the churches appear to be in the process of repositioning the caring role, shifting it from an individual responsibility and obligation of the family towards a community caring role. At present there appears to be no understanding or expectation of how the community will play its caring role. It is not yet clear if the expectation and pressure to support a family member with dementia at home will be helped or hindered by this development, particularly if the community starts to encourage participants to utilise and accept more support from formal health and social care services, including financial entitlements. Family members are ambivalent about taking payment for caring for their relatives. As a result, families have become more dependent on each other for support, not just in terms of responsibilities associated with caring, but with the tasks for maintaining daily living needs, such as buying food and paying bills.

The benefits of inter-family support helps caregivers emotionally, socially and economically. So, while it has been argued that social engagement in general society is eroding (Putnam 2000), we see the opposite in Jamaican communities – a strengthening of social engagement. Communities who may never physically meet are finding ways to communicate because of shared values and interests. Getting information and support is often through personal contacts rather than through health or social care agencies, and Alzheimer's Jamaica was clearly a hub of support for our participants' families, not only in Jamaica but also in England, Canada, and the US.

4.3.6 Theme 6 The Church needs to do more

Having so assertively stated their view regarding the use of care facilities when prompted about expectations for the future, these narratives suggest a more prominent role from the church is needed. There is a sense that dementia has been hitting the Jamaican community in a way no one saw coming, so the response needs to be as a community.

> *… our platforms for change are not with the government, they only pretend to listen, and them stop pretending to care… no, our platform for action is to galvanise the strengths and talents in the church, and from our own people, our own community…*
>
> *P6: lines 360 -363*

> *… there is a thin line between social anarchy and just somewhere to vent. What is the purpose of our leaders and our Pastors? …*
>
> *P8: lines 400-402*

> *... nurses, doctors, social workers, lawyers, pharmacists, pack up in the church, all known to the Pastor, why we can't at least create some sort of signposting for help…I wish someone had been able to help and advise us ...*
>
> *P5: lines 411-413*

> *.. whole heap of[21] qualified, passionate persons in our church who want to do more but where to start… the church can and needs to co-ordinate this better… at the very least provide some information so that the wider church understands more about dementia…*
>
> *P2: lines 299-304*

Participants expressed cynicism about governments caring about families and the realities of their daily experiences.

> *…in this time of austerity, social services does not have the capacity or the resources, even if they had any interest, to be mindful of those of our elders who don't have any children or other family. The church needs to stop going on like it's some sort of happy little country club, and alongside all the other challenges facing us as a community, like our young people dying on the streets, our Pastors need to be raising up dementia champions like we have with diabetes and building services to support those who don't have any children…*
>
> *P1: lines 501-505*

Some participants stated that their families did receive support from their church and church networks but that the church did not provide, as a rule, any organised regular social events for their older members with dementia, or assist with any form of financial support for family caregivers.

> *…church should be offering financial help after years of tithes[22] and offerings*
>
> *P8: line 565*

There was a desire to see dementia better supported in Jamaica and all participants, whatever their experience across the Diaspora, were looking to Jamaica for information, answers and support, and they felt that was where culturally appropriate information would emanate from that would be relevant for them.

[21] There are many
[22] one tenth of income voluntarily paid to the church

> *…this is what those diaspora conferences that we running every other year at such great expense … this is what they should be debating instead of remittances… and other foolishness…*
>
> *P4: lines 372-375*

> *…we were raised by our parents to idealise life, inculcating faith and self-discipline. … the world is not participatory, it is goal orientated. Beyond Sunday school when it comes to the real world you are not going to get an A for effort, you're going to get A for deliverable. Our churches have to deliver…"*
>
> *P8: lines 420 -423*

Narratives highlighted the role church played as a large part of life for all the participants and the care-recipients before the onset of their dementia. With church communities forming large congregations of lifetime friendships, the church and their personal faith did empower the participants to transcend their daily challenges, physically, emotionally and spiritually. So, although there was sadness at the lack of direct support for caregiving up to now, participants spoke of being heartened by recent health conferences, special services, and a noticeable increased willingness of some pastors to seek out people who could offer information and support.

The specific impact of religious institutions on dementia care is under-reported in the literature. Seeman (2000) and Mackinlay (2003, 2009) found that social relationships are beneficial in promoting health in older people and that aspects of the social environment play an important role in health promotion efforts for older adults. The positive effect of church attendance on mental well-being for both care recipients and caregivers found in this study appears consistent with these findings and with other research, such as Holt et al. (2006) and Acton & Miller (2003) who explored spiritual meaning for caregivers of family members with dementia and Regan et al. (2013) who explored whether, in BAME communities, religion hinders access to traditional health care pathways or assists in positive coping.

This study found that religious beliefs and practices instilled from childhood influenced caregivers' daily lives in a positive way. Religious belief and church membership were influential in participants' decision-making processes relating to early diagnosis and accessing services. This is similar to findings by Nooney & Woodrum (2002) who assessed religious coping and church-based social support as mechanisms that explain religious benefits to mental health. Black churches have a long-standing tradition of providing psychological support to maintain ethnic identity within the broader racial, social and cultural environments (Taylor et al. 2005, Bashi 2007, Chatters et al. 2008).

For the participants, the church became pivotal as a source of information and support, as well as maintaining the emotional and spiritual well-being of both care-recipients and the caregivers. Studies among Caribbean communities have demonstrated that there is a reciprocal relationship between health status and social engagement, (Berkman et al. 2000, Seeman 2000, Zunzunegui et al. 2008). Additionally, there is evidence that good social relationships improve longevity, prevent disability and depression, and help maintain cognitive function in old age. Conversely, chronic illness or disability can prevent elders from participating in social activities (PAHO 2005, Rose et al. 2008), and the consequent isolation can be harmful (Seeman 2000). Governments should be encouraged to assist churches in providing more opportunities for the social integration of elders through day-care centres and seniors clubs, which would enable elders to support one another (Zunzunegui et al. 2003).

Blank et al. (2002) show that the Black church in the US has for a long time had a dominant role as an informal social service provider throughout its history, suggesting that churches provide a wide range of prevention and treatment-oriented

programs that contribute significantly to the psychological and physical well-being of their congregations.

The focus on pastors and religious leaders to galvanize resources within local congregations has grown out of findings that paraprofessional counsellors are often as effective as professionals in fostering positive change in the recipients of services (Blank et al. 2002).

The role of churches and the religious community in dementia care and management is under-reported in the literature, but the findings of Zunzunegui et al. (2003) suggest that the governments of England and Jamaica should be encouraged to assist churches in providing more opportunities for the social integration of elders though seniors clubs or day centres which would facilitate support for elders and their caregivers.

4.4 Chapter Summary

Mukadam et al. (2011) and Regan et al. (2013) reiterate that BAME communities are under-represented in specialist services and are initially more likely to fall back on services they are more familiar with, such as faith institutions. While this may be associated with lack of knowledge about dementia or available services (Seabrooke & Milne 2009, Moriarty et.al. 2011), it is important to frame this within the context of culture, race and identity.

The essence of caring experiences captured in these participants' narratives suggests that coping with caregiving for a relative with dementia is a dynamic and transitional process of change for Jamaican families where, particularly for those in England, this is their first encounter with and experience of caring for an elder due to the migratory patterns of the 1950s and 1960s. The study builds on existing

literature about strong networks of family caregivers among BAME families but also adds to the literature which has been monitored by database alerts, by providing an in-depth insight into Jamaican families, showing that, for the majority of families, caring for a person with dementia is seen as an extension of their relational role to the person which is very much tied into, and strengthened by, cultural norms about caring for one's family.

All the participants, in describing their lived experience of dementia caregiving, constructed a narrative based on their upbringing of strong, resilient people, and this construction enabled them to maintain a commitment to upholding the dignity of their elders. The journey for all participants started with negotiating primary care services for information and a diagnosis and re-positioning their lives to be able to accommodate increasing levels of support. They found ways to support their relative in managing all the activities of daily living. This study sought and captured more than just what they did, it captured the essence of familism and carrying out care as a labour of love.

What this study also uncovers is the important role that the church acquires, once the formidable barriers of access to information and specialist services have been negotiated, as an on-going long-term source of understanding, help, and support for both the care-recipients and their caregivers. The churches that participants attended were all lively Pentecostal churches, with majority Black congregations. These churches provided more than just a Sunday morning activity, they were the hub for learning, community activism, social activities and maintaining friendships. The findings revealed an urgent need for more organised activities and services within the church to include members with dementia and allow caregivers to remain part of these fellowships.

Chapter 5 Conclusion and recommendations

5.1 Introduction

This chapter revisits the research aim and objectives and outlines key findings. The original contributions to knowledge are highlighted and the strengths and constraints of the study are reviewed. Recommendations for practice, and suggestions for further research are presented. The chapter's penultimate section describes how the study findings will be disseminated. The chapter's closing section provides a reflection and a critical review of the research experience from the point of view of a novice researcher undertaking a study towards a Professional Doctorate.

5.2 Revisiting the research aim and objectives

The study aimed to explore the lived experience of dementia caregiving by caregivers of Jamaican heritage living in England and Jamaica. To achieve this the following objectives were identified:

1. To explore the experiences of family caregivers in England and Jamaica
2. To explore influences that impact on family caregivers' ability to provide care and cope with their role
3. To explore the expectations of family caregivers for long-term care provision for their elders

Ten participants were recruited: 5 caregiving in England, and 5 caregiving in Jamaica. Data were collected from interviews. Using Experiential Thematic analysis (Braun & Clarke 2013), six themes developed which were titled using quotes from participants and presented using the Data Excerpts Approach (Reay et al. 2019).

A summary of the themes is presented below.

(i) Strength and resilience

Narratives from participants in England and Jamaica described Jamaicans as proud people whose identity was associated with strength. Participants were striving to demonstrate a strength similar to that shown by the older generation and to achieve and succeed as their elders had done, and this influenced their optimism about whatever challenges lay ahead regarding their caregiving role.

(ii) Labour of love

Linking with Theme 4, this theme described the thoughts and feelings of their day-to-day experiences of caregiving and revealed that, despite some very challenging days, there was a willingness to fulfil an expectation that elders would be cared for at home, even if care facilities might be available. In Jamaica, where the obligation for kinship caring is still legislated under the Maintenance Act (2005), the overriding reason for maintaining care at home did not appear to be tied to the legal obligation but was indeed a labour of love, underpinned by respect and desire to maintain dignity for their elders.

(iii) Picking sense out of nonsense

This theme captured caregiver experiences of living amid sophisticated 21st-century health and social care systems that seemed incapable of dealing with people with dementia. Participants expressed bewilderment that with so much research purportedly taking place, with health professionals and support staff receiving dementia training and copious publicity about dementia, it was still an ordeal to make or attend a simple GP/primary physician appointment.

(iv) I'm not a carer – I'm family

Despite widespread adoption of the term carer across the literature and within services, participants resisted identifying themselves as carers, instead seeing their role as a wholly natural extension of their familial relationship with the care recipient. In England, no participant had become a Registered Carer, even though being ascribed that official status may have made them eligible for extra resources and benefits such as Carers Allowance. In Jamaica, care for older relatives is legislated for in the Maintenance Act (2005) as a familial duty and obligation so this was not an issue.

(v) Jamaican's don't do that

Participants expressed feelings of hurt and disappointment at the contemplation of maybe having to place their relative in a care facility for long-term care. Linked to theme 2, the value families put upon being able to care long-term for a family member living with dementia linked with other findings in the literature about familism (Parveen et al. 2014 Lawrence et al. 2008).

(vi) The church needs to do more

This theme was captured in narratives that suggested a more prominent role was needed from the church. There was a notion that dementia was hitting the Jamaican community in ways no one saw coming, so the response needed to be as a community. The role of the church in the care and management of dementia is underreported in the literature, but health and seeking help behaviours are affected by many different factors and the biomedical settings of primary care and hospitals were not the only

option to influence health behaviour. The church provided what Symthe (2005:489-490) describes as 'therapeutic spaces' and 'therapeutic networks' through which people gain support and care, often outside the biomedical tradition adding to the literature on therapeutic landscapes which arise when the physical and built environments, social conditions, and human perceptions combine to produce and atmosphere which is conductive to well-being. This study supports the findings of Zunzunegui (2003) that suggest that the governments of England and Jamaica should be encouraged to assist churches in providing more opportunities for the social integration of elders through seniors clubs in order to help facilitate support for both elders and their caregivers.

5.3 Original contributions to knowledge and professional practice

The contribution this study makes is that it will be the first published qualitative study to explore the lived experience of caregivers of Jamaican heritage caring for a family member living with dementia. Identity as Jamaicans appears to have a powerful and positive influence on caregivers' capacity to cope with caregiving, linking their individual, family and national identities with the determination to survive all challenges. While there are studies on Caribbean families (Griffith and Grolnick 2013), the influence of cultural factors (Downs 2000), and resilience (Lampley-Dallas 2001, Cox 2007, Botsford et al. 2011, Valdez 2013), this study's contribution is the discovery of a connection between how the participants were raised and how that has helped to build their resilience to cope with the challenges of caregiving for their elders living with dementia. This finding also speaks to the socio-cultural issue of caregiving responsibility falling predominately on women within BAME communities

usually identified as a daughter or daughter-in-law (Jutlla 2010). So, while this study builds on existing studies such as Milne and Chyssanthopoulou (2005) who identified that women from BAME communities are culturally primed to provide most of the caregiving for a relative living with dementia, it extends existing knowledge by showing how women of Jamaican heritage use their strength, expertise, availability, and understanding of their family's dynamics to include wider extended family members and thereby skilfully negotiate sharing care across the entire family when caregiving in both England and Jamaica as shown in the discussion of Theme 4 of this study.

Policy advisors posited in Right Care, Right Here (2012) that changes in BAME family structures might mean fewer family carers willing or able to look after family members at home leading to an increased need for long-term care facilities. The findings of this study do not support the notion that Jamaican families are pressing for an increase in the provision of long-term care facilities in England or pushing for the provision of such facilities in Jamaica. Instead, caregivers are looking to the church and the Jamaican community to organise support and signposting of services that will enable elders to receive long-term care in a family environment, looked after by family and friends. While the social activism of the church in dementia care and management is underreported in the literature, this study supports the findings of Mir et al. (2016) that showed how faith, and religious belief can be used effectively to help people cope with and manage health conditions and Zunzunegui et al. (2003) that governments should be encouraged to assist churches in providing more opportunities for the care and social integration of elders which would facilitate support for elders and their caregivers. Putnam (2000) argued that social engagement is eroding, the findings of this study argue, instead, that within

Jamaican communities' social engagement is evolving and strengthening, shown in this study by the 'bridging' and 'linking' capital of the church. Cloutterbuck and Mahoney (2003) argue that religion does not have a significant influence on caregivers; the findings of this study contradicts this. Faith was part of the context in which participants understood and experienced dementia and the church was a source of strength. with prayer very much a part their toolkit. Health and seeking help behaviours are affected by many different factors and the biomedical settings of primary care and hospitals were not the only option to influence health behaviour. The church provided what Symthe (2005:489-490) describes as 'therapeutic spaces' and 'therapeutic networks' through which people gain support and care, often outside the biomedical tradition adding to the literature on therapeutic landscapes which arise when the physical and built environments, social conditions, and human perceptions combine to produce and atmosphere which is conductive to well-being. This study's methodology and findings will assist other researchers conducting qualitative interviews with participants from the Jamaican community by helping to challenge the notion that it is difficult to recruit from this community (Rockliffe et al. 2018). This study has established that by using a recruiting strategy that includes churches, participants are readily reachable. As this study highlighted in Theme 6 the church plays an important role in the lives of many individuals in the Jamaican community, and therefore can be a good place to facilitate public engagement and disseminate health promotion-related messages. Churches are often not seen this way. However, if health professionals want to engage with the Jamaican community and gain their confidence to ensure greater involvement in research and within mainstream services, they need to understand the importance of the church for the

Jamaican community. In addition, they need to find ways to engage with Pastors and leaders, considering their influential positions.

I cannot claim that this study captured all the factors influencing the lived experiences of Jamaican family caregivers. Instead, I offer a perspective that may be common among a community, some of whom are already marginalised due to their ethnicity. This study provides insights into the life experiences of a group of people who have witnessed the challenges of migration, watched parents ageing and develop dementia, without prior exposure to caring for elders, due to grandparents remaining in Jamaica for much of their childhood. These are findings that are not present in previous studies of the BAME or African Caribbean communities in England.

5.4 Critique of the study

The strengths and constraints of this study are considered using the broad qualitative criteria of Tracy (2010). Tracy (2010) states good qualitative research is relevant, timely, significant, interesting or evocative. The World Health Organisation (2012) report that the total number of people with dementia worldwide in 2010 was estimated at 35.6 million and is projected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying one new case every four seconds. Dementia is overwhelming, not only for the people who have it but also for their caregivers and families. The literature highlights how caregivers from BAME communities differ in their experience from the white British community in England, yet the evidence base for care in BAME communities remains profoundly limited.

This study encompassed caregivers with dementia caregiving experience in England and Jamaica, and the way these narratives overlap with previously identified findings within other BAME groups suggests good transferability. The literature review sought to highlight what was known about dementia in BAME communities and acknowledge the gap in our knowledge about the Jamaican community, that allowed for building on previous work as described by Grant and Booth (2009). Although a systemic approach was used, it is acknowledged by Grant and Booth (2009) that combining diverse sources of evidence can be complex and challenging and can lead to a selection of literature that supports the proclivities of the researcher.

I highlighted in the methodology chapter that, throughout the early part of the data collection, it was important to acknowledge that insider outsider researcher status had inherent challenges (Serrant-Green 2002). This study has demonstrated that when seeking to understand experiences in the Jamaican community, while it helped to be knowledgeable about and responsive to Jamaican culture in a genuine way by understanding that Jamaican elders are honoured and treated with respect, as a woman of Jamaican heritage myself, former caregiver for a family member, (insider) and as a researcher (outsider) I had to place myself within the research, examining my identity alongside that of the participants. This called for me to consider my role in the research and the effect of my own socialisation and life experiences might have on the study. However, as Heugten (2004) suggests that bias and subjectivity, due to insider status was ameliorated by remaining honest and open about difficulties that arise and diligent self-examination.

Tracy (2010) proposes the need for rigour within qualitative research, emphasising the requirement for sufficient data to support claims. A substantial amount of time was spent collecting rich data in the form of in-depth interviews, which was justified within the methodology in terms of ethics, sample size approach and detailed processes of analysis. However, in conducting a study that involved international travel between England and Jamaica, it was found that, while those born in England, (or other countries across the Diaspora), of Jamaican parents appear to assimilate, they do not ever actually dilute their culture wherever they happen to live. There were occasions I had to double-check which country I was actually in. So, while the findings cannot be considered generalisable to other populations, it does add to the knowledge base of dementia caregiving in BAME communities.

Tracy (2010) asserts that research findings need to reverberate with the reader. Resonance was attempted through the verbatim quotations used within the findings and discussion chapter. It is acknowledged that there can be different interpretations of what is deemed most significant in the participant transcripts, but using Reay (2019) Data Excerpts approach within a phenomenological methodology has, I believe, provided enough thick description to provide narratives that are vivid and engaging and that allow readers to come to their own conclusion about the interview exchanges. All the participants, in describing their experience of dementia and caregiving, constructed a narrative based on their upbringing of strong, resilient people, committed to maintaining dignity for their elders. The journey for all participants started with negotiating Primary Care services for information and a diagnosis, and re-positioning their lives to be able to accommodate increasing levels of support. They found a way to support their relative whilst still managing all the activities of daily living. This study sought and captured more than just what they did,

it captured why they did it, which greatly influenced their thoughts regarding longer care and their strong resistance to contemplating admission to nursing homes and shown in the Theme 5 of findings.

5.5 Recommendations for practice

Mobilising the experience and resilience of UK community organisations is an important means to building greater confidence and civic participation for the Jamaican community. Yet, despite recommendations by Jolley et al. (2009) that have been available since the early days of the first UK National Dementia Strategy (DH 2009), repeated in the 2016 update (DH 2016), there has been little uptake in the use of third sector community organisations by the health commissioners who are the key decision makers in the allocation of financial resources for developing dementia services. Third sector community organisations often have substantial knowledge and active involvement with BAME communities and can provide an accessible route through sustained support networks.

Culture Dementia UK, one such organisation, posits that, for most African Caribbean families living with dementia, the care pathway in Figure 5:1 below is the current experience. This illustrates how the person with dementia and the lives of their caregivers become increasingly isolated, until either the person living with dementia or their caregiver has a health crisis, often ceasing to be able to continue to care, or the person living with dementia no longer being able to manage with home-based support.

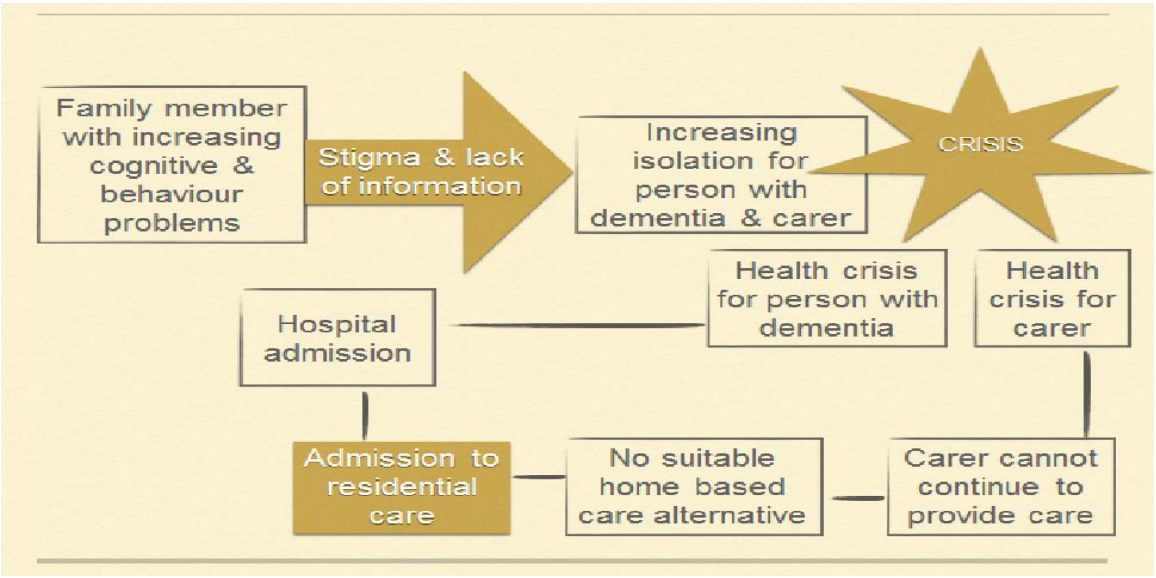

Figure 5:1 Current dementia care pathway for African Caribbean community (Truswell 2016)

Culture Dementia UK promote the following improvement to the dementia pathway (Figure 5:2).

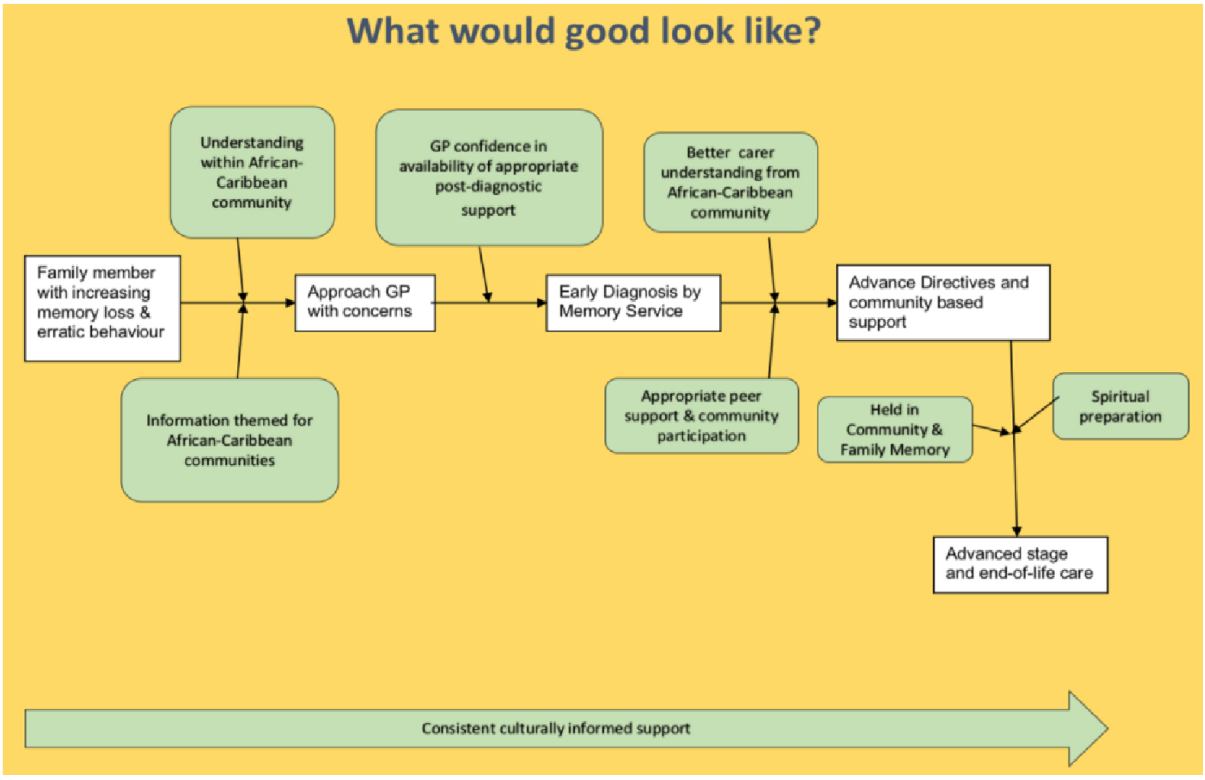

Figure 5:2 What would a good care pathway could look like? (Truswell 2016)

NHS England has committed to improving the quality of services for people with dementia by placing patient experience at the heart of the commissioning process (NHS England 2017). In addition to this, there is a clear recognition that the commissioning process should give regard to the need to reduce inequalities in access to, and outcomes from, health and social care services, and to ensure that all services are provided in an integrated way (NHS England 2017). This study's findings suggest that commissioners of dementia and healthcare care services need to recognise the importance of voluntary community groups, and the Black churches when collating and disseminating information and creating public health promotions.

This study's findings show that caregivers recognise the importance and value of social interaction with their churches, both for themselves and their relative. For the church, the implications for practice are that there is a need for education and awareness-raising about dementia and that pastors and other church leaders need to identify dementia champions who will provide resources for support. This will have a profound and positive impact on families living with dementia, the wider church family, and the community. A key action that I would hope to spearhead, using my previous professional experience in roles such as Birmingham Chair for the Nurses Association of Jamaica (UK) and Health Lead West Midlands Branch for Jamaican Diaspora (UK), is the development of a repository of information for sharing and galvanising expertise through community contacts and the church, to support health and social care agencies. This would include encouraging an organisation such as Alzheimer's Jamaica in Kingston to become a support hub for families to access – one which could be duplicated in England.

The 2020 vision, highlighted in the National Dementia Strategy (DH 2015), was fuelled by a desire to be person-centred in its approach. People with dementia and their caregivers often have unique insights into their condition and lives, so they should be involved in formulating the policies, plans, laws and services that relate to them. Health and social care professionals can help improve the care that is delivered to Jamaican families by attempting to better understand the personal histories and cultural context of this community. There is a need for cultural competency training for those working with Jamaican families. Most importantly such education and training should highlight the importance of migration experiences not currently given due regard in reminiscence groups within current Older Persons assessment units or in social care assessments and as highlighted in participant narratives in Theme 3.

It is becoming established that the increase for dementia caregiving in the Jamaican community is due to persons of Jamaican heritage being at special risk of developing vascular dementia because of the greater incidence of diabetes and hypertension compared with the general population. Jamaica is forging ahead with discovering more about the clinical implications of this (Eldemire-Shearer 2017). However, there is limited work being undertaken in England to develop a programme of targeted health promotion or preventative work (Jeraj and Butt 2018) at either local or national levels. A National Dementia Plan is the single most powerful tool to improve dementia care and provide additional support. Currently, only 11 countries around the world have developed, or are currently implementing, National Dementia Plans (ADI 2013) so there is much to focus on, and work to be done, in the next few years.

5.6 Suggestions for further research

Dilworth-Anderson et al. (2002b) provide a review of research covering the 20-year period of 1980-2000, in which they conclude that there is a clear consensus that older people from minority ethnic communities use more informal networks of support - not just close family but also distant family members - to provide care. The fact that a significantly higher proportion of Jamaican elders live alone and have no children or family than is the case for other BAME populations (ONS 2011) might have implications for the nature and pattern of support required. The implication for practice is that there is an urgent need to provide support for people with dementia who are childless and have no wider family support.

This study is an interpretation of dementia as experienced through the eyes of Jamaican caregivers. There is further research potential here, as the perspectives in my work are my interpretation. Further research is also suggested with larger samples focusing on other key groups such as church organisations to explore their perspectives of their role, in supporting caregiving within Jamaican families.

5.7 Dissemination of findings

The All-Party Parliamentary Group on dementia released a report in 2013 (AAPG 2013) which contained seven recommendations with regard to BAME communities. Two key recommendations were i) to raise awareness of dementia in these communities and ii) to improve access to high-quality dementia services. Based on these key recommendations, funding is being sought for a series of dementia awareness-raising roadshows. It is planned that the findings of this study will be submitted for publication in relevant professional peer-reviewed journals, and presented locally, nationally, and internationally at appropriate health and research

conferences, many of which are now moving online due to COVID-19 restrictions, so the ability to engage with a range of interested audiences is enhanced.

5.8 Concluding reflections

Completing this study, which was accompanied by many challenges, has helped me develop both as a researcher and as a person. The 'taught' component of the doctorate programme presented a challenging start. The first paper was titled "*position yourself as a researcher, on the basis of individual preference, prior experience and reading, within one of the major research approaches, and justify this in relation to its underpinning epistemological and ontological assumptions*". Epistemological and ontological what! Despite having completed two degrees at Masters level, I had quite limited knowledge of philosophical stances and methodologies and until I started doctoral study the words epistemological and ontological were definitely not part of my everyday vocabulary. Philosophers, I soon discovered, have their own vocabulary which includes the use of words and pseudo-profundity as a way of making their work seem more difficult than it really is. I eased myself gently into this world by becoming thoroughly absorbed in the wonderful novel Sophie's World (Gaarder 2007), and Delanty and Strydom's (2003) Philosophies of Social Science: the classic and contemporary readings.

I started a research journal to plot reflexive experiences, critical thoughts and observations as I attempted to identify *my* philosophical world view. Very quickly I began to realise that who I am is a product of my education, gender, race, culture and beliefs, and I would therefore have to be very pragmatic in recognising that all of these could potentially influence my positioning. Despite years of education and a professional career in nursing of nearly forty years, I discovered that the impact of my formative years has been profound. I grew up believing that there were things that existed beyond my knowing, but that my awareness was limited to those things I had come into contact with through my senses. I believed that there were things that

would always be beyond my knowing, things I could not touch or feel but were nevertheless real, because the Bible was (and still is) my epistemological framework. Audi (2001) stated that epistemology is concerned with how we know what we do; what justifies us in believing what we do; and what standards of evidence we choose to use in seeking truths about the world and human experience. So, during extensive reading, I came to the first important landmark on my journey – the discovery that I was neither essentialist nor positivist in my thinking, as I had believed, but that I appeared to be diametrically opposed to these views of seeing the world. Was I really? Audi (2001) stated that even well-grounded beliefs can be mistaken, and we are all fallible in perceptual matters, as in our memories, in our reasoning, and in other respects. My epistemological integrity felt compromised but, according to Ersser (2001) knowledge only has the potential to become propositional knowledge once it has been articulated, then debated, contested, and verified through wider communities of practice.

The next realisation was the impact that my professional work roles had had over the years on the way I viewed the purpose and outcome of research. Watson and Keady (2008) state that research serves many purposes; at one end of the continuum it serves to generate new knowledge; at the other end of the continuum, research serves to solve problems. I was a problem solver. As a senior nurse leading Practice Development, I had been driven by reports and deadlines and had, over time, blurred the lines between research, audits and service reviews, as I had become programmed to deliver findings, outcomes, and recommendations. My entire thinking was being deconstructed. Moving onto the research methods modules, systematic reviews and statistics put me back in my comfort zone for a while. The numerous statistical approaches that are adopted to demonstrate the

efficacy of interventions was a useful revision of information that I had learned and used over many years in practice and with post-graduate studies. For much of my career as a practitioner, and while working as nurse educator in higher education, I have strived to achieve improvement in practice using the best available evidence. One of the first revealed outcomes during this module was that, essentially, I seemed to be a positivist. I liked evidence. I looked for evidence. This might explain why I enjoyed doing my LLM (Mental Health Law) far more than my MSc (Advanced Nursing Practice). Legal research is fundamentally the ability to locate and examine case law. No other literature is considered worthy of examination until all appropriate cases have been investigated. Only by appraising the case law does it become apparent what other type of literature might be relevant for further investigation.

Qualitative enquiry was unfamiliar, with its underpinning philosophical beliefs about values, concepts, and the nature of knowledge itself. To understand these philosophical perspectives, I read in earnest. The most helpful at that time was Creswell (2007), Qualitative Inquiry and Research Design: Choosing among five approaches. This text was a useful, practical, comprehensive and reader-friendly guide for a novice qualitative researcher and was an enormous support to my learning. Accessing online lectures by Dr Jason Campbell[23], based at the Nova South Eastern University, Fort Lauderdale, Florida, suited my learning style and provided supplementary information.

I knew I wanted my research project to focus on family caregivers here in the England and in Jamaica, to understand how personal histories had influenced experiences of caring for a family member with dementia. My first intention was to

[23] https://www.youtube.com/watch?v=7IDva7tzliA&list=PL809EFFA210C27775

investigate if there might be some ontological basis to support Validation Therapy[24] (a therapy not currently used in England) as an intervention to improve the outcomes for people with dementia, emphasising, as Validation Therapy does, the importance of migrant experiences and cultural interpretations. But as it became increasingly apparent that Jamaican family caregivers were almost invisible to services and policy makers, I came to see as a very bold assumption of perceived value or need on my part. So, during a process of refocusing, I learned that reviewing the literature required much more than the technical knowhow of how to locate information. The real art of doing a good literature search was the ability to understand that sometimes it may be appropriate not to attempt to locate information, because in doing so one may merely be seeking to answer a question no-one really cares about, and in so doing not allow data to generate another line of enquiry that may just bring out that more interesting question! Maso (2003) recommends using the 'why interview ('why this, why not that?') to clarify and refine one's research interest, placing plans under a spotlight until a more satisfactory version emerges. Thus, in attempting to locate the focus and key question for my study, found myself concurring with Beckford-Ball (2009) when he states that if one was really serious about tackling dementia, it is the day to day care of people living with the condition, and the experiences of their family caregivers that needs to be explored and addressed.

Progression to the Thesis module of the professional doctorate felt invigorating. The aim of my research project was now going to be the investigation of the experience

[24] Validation therapy was developed by Naomi Feil between 1963 and 1980 for older people with cognitive impairments. Initially, this did not include those with organically based dementia, but the approach has subsequently been applied in work with people who have a dementia diagnosis. Feil's own approach classifies individuals with cognitive impairment as having one of four stages in a continuum of dementia: these stages are Mal orientation, Time Confusion, Repetitive Motion and Vegetation. The therapy is based on the general principle of validation, the acceptance of the reality and personal truth of another's experience and incorporates a range of specific techniques.

dementia caregiving by caregivers of Jamaican heritage living in England and Jamaica. I was going to be undertaking a study which would involve spending time working in Jamaica. One of the biggest challenges that had to be overcome was breaking down the barriers of mistrust the Jamaican community had regarding any thing or any persons linked with mental health services, in order to even open a dialogue. This study was the first occasion in which I would undertake qualitative research and a key concern, despite having read several textbooks and watching numerous videos, was the lack of my direct experience interviewing people for research purposes. Pilot interviews proved the best way to prepare for data collection and they informed my approach for the study.

My career progression has always been aligned with the drive for continual learning to enhance my professional development. Each career move and postgraduate study has helped to shape my thinking and refine my ideas in terms of communication, leadership, and gaps in knowledge and awareness. My personal and professional development has been characterised by the need to challenge my own boundaries. Perhaps one of the most significant insights that I have gained in recent years is to realise I am more resilient that I ever imagined I could be. Completing this research has been part of this journey and my passion for nursing and the enhancement of care. Contributing to ongoing practice-based research will play an important role in my future.

I hope that the findings of this study will contribute to the growing body of literature that represents a generation of Black nurse researchers giving a voice to our communities.

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Appendices

Appendix 1

The Biomedical Model of Dementia

The biomedical model focuses on physiological damage. Dementia symptoms appear when damage occurs in brain cells which stop them from communicating effectively with each other and gradually these brain cells die (Cummings 2003). Physiologically, everything we do is controlled by the brain. The brain is the most complex organ in the body. In a typical human, the cerebral cortex is estimated to contain 15–33 billion neurons (Pelvig et al. 2008) each connected by synapses to several thousand other neurons. These neurons communicate with one another by means of long protoplasmic fibres called axons, which carry trains of signal pulses to distant parts of the brain or body, targeting specific cells. This centralised control allows rapid and coordinated responses to changes in the environment. Some basic types of responses such as reflexes can be mediated by the spinal cord or peripheral ganglia, but sophisticated purposeful control of behaviour based on complex sensory input requires that information is centralised by the brain. The operations of individual brain cells are now understood in considerable detail but the way they cooperate in ensembles of millions is yet to be solved (Yuste and Church 2014). Recent models in modern neuroscience treat the brain as a huge biological computer, in the sense that it acquires information from the surrounding world, stores it, and processes it in a variety of ways. The functions of the brain presented here are related purely to the context of understanding the symptoms of dementia within the biomedical model and the damage to this processing system.

The following outlines current understanding of brain function and the course of development of the most common forms of dementia.

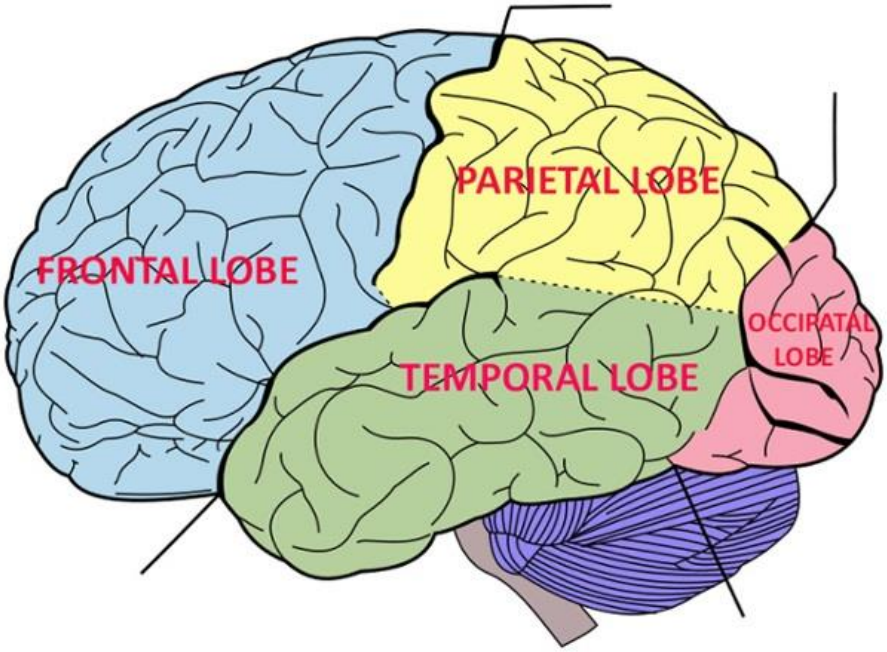

Diagram 1: Source : Bournemouth University (2016)

The Frontal lobe of the brain controls language skills, the ability to organise, the ability to think. It defines personality and regulates behaviours. Damage to the frontal lobe causes individuals to lose the ability to empathise with others which can make them appear selfish. They may become extrovert when they were previously introverted, or withdrawn when they were previously outgoing. They may behave inappropriately - for example, making tactless comments, joking inappropriately, or being rude. They may lose their inhibitions - for example, exhibiting sexual behaviour in public, or they may become aggressive. They may become easily distracted, or develop routines or compulsive rituals.

The Temporal lobe controls recent memory recall, the ability to learn and remember new information, verbal memories such as names and faces of people. Damage to the temporal lobe would cause individuals to, for example, not be able to remember instructions, or how to use ordinary household gadgets such as switching on a kettle. In addition they may not be able to remember events, appointments, telephone conversations or family visits.

The Occipital lobe controls the ability to process information from the eyes. The ability to see objects is achieved by the eyes, but the ability to make sense of what we see is the job of the occipital lobe. Damage to the occipital lobe would, for example, reduce the ability to judge distances, or reach out for things. Individuals may take high steps overshadows because the change in colour looks like a change in level, and they may become easily lost and disorientated in familiar environments.

The Parietal lobes have an important role in integrating our senses. In most people the left side parietal lobe is thought of as dominant because of the way it structures information to allow us to do tasks such as reading and writing, calculations, perceiving objects, and producing language. Damage to the non-dominant lobe, usually the right side of the brain, results in different problems. The non-dominant lobe receives information from the occipital lobe and helps us to 'picture' the world around us. Damage may result in an inability to recognise faces, surroundings or objects. So someone may recognise a voice, but not the appearance (‘you sound like my daughter, but you're not her’). This lobe has a role in helping us to locate objects in our personal space, and damage would lead to constructional apraxia (problems with skilled movements) required for activities such as drawing, writing or picking up objects.

With **Alzheimer's disease,** the most common cause of dementia, our current understanding is that ‘plaques’ and 'tangles' develop in the structure of the brain, leading to the death of brain cells. Alzheimer’s disease develops slowly and gradually, and onset is usually marked by: lapses of memory; mood swings; difficulties finding the right words; noticable marked changes in usual behaviour; withdrawal of interest. As the illness progresses, the person may become confused and more dependent on other people for help with everyday activities.

Vascular Dementia, the second most common type of dementia, is the result of inadequate blood flow. Inadequate blood flow can damage and eventually kill cells anywhere in the body, and as the brain has one of the body's richest networks of blood vessels it is therefore especially vulnerable. Multiple small strokes or other conditions that affect blood vessels and nerve fibres deep inside the brain cause gradual thinking changes as damage accumulates (Stroke Association 2012). Common early signs of widespread small vessel damage include impaired planning and judgement; declining ability to pay attention; difficulty of comprehension when doing routine tasks; confusion; irritability; aggression; or difficulty finding the right words. Vascular dementia usually progresses in stages, each stage consisting of some deterioration with a period of partial recovery. Individuals may have long periods of lucidity, and symptoms may fluctuate, making diagnosis and management very challenging. As the damage progresses, the individual may become increasingly confused, and frequently forget the names of people, places and recent events. They may feel scared and frustrated by their increasing memory loss and become more withdrawn, due either to a loss of confidence or to communication problems.

Lewy Body Disease, which is very similar to Alzheimer's Disease, is characterised by deposits of the protein alpha-synuclein inside brain cells. Lewy bodies are abnormal aggregates or 'clumps' of this protein. When they develop in a part of the brain called the cortex, dementia can result. [Alpha-synuclein also aggregates in the brains of people with Parkinson's disease, but appear in a different pattern from dementia with Lewy bodies]. Onset is gradual and early symptoms include changes to language, memory and the ability to judge space and distance, as well as slowness of movement; stiffness and tremors. As the damage progresses, individuals may show extreme states of confusion – which may vary in degree from day to day, they may experience hallucinations (hearing or visual), or delusions, have severe tremors or jerkiness, and become depressed. In some cases the heart rate and blood pressure are affected and may result in unsteady balance/fainting. Abilities and moods can fluctuate and change very quickly, which can make life very puzzling and challenging for caregivers.

Extract from Jamaica Maintenance Act 2005

PART V. Obligation - person who is not a minor

10.—(1)Every person who is not a minor has an obligation, to the extent that the person is capable of doing so, to maintain the support of parents and grandparents who are in need of such maintenance by reason of age, physical or mental infirmity or disability.

(2)In considering the circumstances of a dependant who is a parent or grandparent, the Court shall have regard to whether, by reason of age or infirmity, that dependant is unable to provide for himself or herself.

(3)The obligation of a person under subsection (l) in respect of that person's grandparent only arises in the event of the failure of the grandparent's children to do so owing to death, physical or mental infirmity or disability.

Appendix 2

Quality screening of literature using CASP (2014)

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues addressed	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to my study
Baghirathan S & Cheston R (2018) A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities Dementia **19** (5) 1672-1691 (UK)	To explore the experiences of caregivers from South Asian African Caribbean and Chinese communities in Bristol to generate a grounded theory	Grounded Theory (Strauss & Corbin 1990)	Purposive and snowballing (47 from South Asian communities 31 from Chinese community 25 from African Caribbean community)	Interviews with 27 participants and 8 Focus Groups for 76 participants	Study was overseen by a steering group that included from local BAME VSCOs. A female research with experience of the local BAME communities was employed to do interviews and conduct focus groups	Study approval from ethics committee of Faculty of Health and Applied Sciences at UWE	Analysis and data collection carried out concurrently Open coding and constant comparative to generated themes	The theory of diminishment – balancing the need for support against the need not to be diminished by that support	Supports BAME remain underrepresented in specialist dementia services and more likely to draw on support from family and religious institutions
Berwald S Roche M Adlelman S Mukadam N & Livingston G (2016) Black African and Caribbean British communities perception of memory problems We don't do dementia PLoS One, **11**(4), e0151878. (UK)	To explore the barriers to help seeking for memory problems with UK Black African and Caribbean communities	Yes	Purposive and snowballing 28 Black African 14 Black Caribbean 7 Black British 1 Indo Caribbean Stopped recruiting when no new themes were arising	Semi structured interviews using vignettes & 8 Focus groups participants given choice	No discussion of reflexivity	Study approved by the National Research Ethics Committee East of England – Hatfield Participants given gift voucher as thank you for time	Anonymised Interview scripts sent to participants to comment on accuracy. NVivo used to manage and analyse data Thematic analysis	While many people recognised forgetfulness, some thought dementia was a White persons illness.	While a GP cannot necessarily spend a long time with individual patients, they want people with memory problems to see them. They can they appropriately refer those with possible dementia to memory clinics where they will be time available and whose role it is to prolong independence and support families in caring.

Screening questions	**Clear aim?**	**Research design appropriate to address aim?**	**Recruitment strategy appropriate?**	**How was data collected?**	**Reflexivity**	**Ethical issues**	**Data Analysis rigorous**	**clear statement of findings?**	**How valuable is the research/ relevance to my study**
Samson Z Parker M Dye C and Hepburn K (2016) Experiences and learning needs of African American family dementia caregivers American Journal of Alzheimer's Disease and other dementias **31** (6) 492-501 (US)	To explore how issues of race and culture can be incorporated into culturally sensitive interventions	Grounded Theory	Purposive 32 caregivers (All African American)	4 Focus Groups using scripted questions	No discussion of reflexivity	Participants were given a $25 honorarium	Two independent coders who compared and agreed final themes	Tradition of family care. Navigating without help.	Adds to knowledge about African American caregiving highlighting specific planning needs Participants regretted lack of long term planning that cultural emphasis on privacy particularly around medical needs has created. Found it difficult to locate information in own communities.
Sun F (2014) Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia Dementia **13** (6) 803-818 (US)	To explore stressors and coping strategies of family caregivers living in Shanghai China	Yes	Purposive 18 Caregivers (All Chinese)	Qualitative Interviews	No discussion of reflexivity	Institutional Review Board Arizona State University	Thematic Analysis Hsieh and Shannon 2005)	General two types of coping - problem focussed, and emotion focussed (Lazarus and Folkman 1984)	Compared to the experiences of Chinese Americans Chinese families in this study experience more challenges accessing treatment and support, had fewer care facilities and less formal family support. Caregivers need to be empowered to be involved in formulating policies plans and services

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to my study
Botsford J Clarke C & Gibb C (2011) Dementia and relationships: experiences of partners in minority ethnic communities Journal of Advanced Nursing **68** (10) 2207 2217 (UK)	To report the experiences of partners of African Caribbean and Greek Cypriot partners of people with dementia and to contribute to understandings of the impact of ethnic background on the experiences of partners of people with dementia.	Grounded Theory (Glaser & Strauss 1967 Strauss & Corbin 1998 Charmaz 2006)	Purposive 13 participants (6 Caribbean 7 Greek Cypriot)	In-depth interviews	Greek participants offered interpreter for interview.	Approval from University and NHS Research Ethics committee	Guided by grounded theory principles data collection and analysis done concurrently. Data saturation was achieved after 43 interviews	An active process of redefining relationships occurs in the context of having a partner with dementia Greek Cypriot and African Caribbean people may delay in accessing a dementia diagnosis or support Ethnic background is important in relation to whether family or formal care is preferred by partners of people with dementia	Nurses and other healthcare professionals need to recognise uniqueness of individuals in the context of their ethnicity Understanding cultural preferences around caring and family relationships will assist nurses to support people to maintain relationships and access appropriate support
Mukadam N Cooper C Basit B & Livingston G (2011) Why do ethnic elders present later to dementia services? A qualitative study International Psychogeriatrics 23 (7) 1070-1077 (UK)	To explore the link between attitudes to help seeking for dementia in BAME communities and the indigenous population	Yes	Purposive sampling 18 caregivers (5 South Asian, 1 Asian other, 1 5 Black (African or Caribbean) 1 White Irish 1 White other, 1 Chinese)	Semi structured interviews	Not discussed	Approval from East London and the City REC Alpha ethic committee, and Camden and Islington NHS Trust R & D department.	Coded using ATLAS-ti v5.6 Coding began after first five interviews to incorporate emerging themes into subsequent interviews. Themes identified independently by each researcher using Corbin and Strauss (1990) then compared and agreed	ME carers as opposed to indigenous carers did not like seeking help from outside agencies as they felt it intrusive. Minority carers believed dementia symptoms to be part of normal aging.	First study to explore how carers from different ethnic groups decide when to access health services. Minority ethnic carers tended to think that families should look after their own. Mixture of familial responsibility and negative perceptions of mental health services.

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to my study
Parveen S Morrison V & Robinson C (2011) Ethnic variations in the caregiver role: A qualitative study Journal of Health Psychology 16 (6) 862-872 (UK)	The convergence and divergence of experiences of caregivers from four ethnic groups	Yes	Purposive 30 caregivers (8 British Bangladeshi 9 British Indian 4 British Pakistani 9 White British) 28 women 2 men	5 focus groups	No discussion of reflexivity	Approval from University Ethics Committee Participants received a surprise payment of £10 (i.e. payment was not offered as part of the consent procedure)	Coping data coded in focus group using Carver (1997) model of coping) Transcripts analysed using thematic content analysis (Braun and Clarke 2006)	Caregivers felt they had no choice but to adopt the role of caregiver. BB BI and BP willing to provide care but underlying motivation was related to cultural and religious obligations.	Consistent with quantitative literature on caregiving all participants reported both positive and negative aspects to their role Motivations and willingness to provide care should be considered by professionals working to support family caregivers in distress
Jutlla K (2011) Caring for a person with dementia: a qualitative study of the experiences of the Sikh community in Wolverhampton Generations Review 20 (3) (UK)	To identify how migration experiences and personal histories influence experiences of caring for a person with dementia for Sikhs living in Wolverhampton	Grounded Theory	Purposive 12 caregivers (All South Asian) 9 women 3 men	In depth narrative interviews	Discussed insider research	Approval from Keele University Ethics Committee	NVivo 7 used for open coding Conditional/ consequential matrix uses as additional tool	Migration experience important for understanding caregivers' experiences Strong cultural norms around gendered roles Participants viewed their caring role as an extension of existing obligation and identity	Participants experience of caregiving dependent upon continuing repositioning between caring role and relational role Findings can only be generalised to caregivers in a Sikh community who have migrated to the UK

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to my study
Jolley D Moreland N Read K Kaur H Jutlla K & Clarke M (2009) The twice a child projects: Learning about dementia within the Black and minority ethnic population of an English city and improving services Ethnicity and Inequalities in Health and Social Care **2** (4) 4-9 (UK)	To learn about dementia within BME groups and how to improve services	Yes	Purposive 30 caregivers 10 African Caribbean 20 South Asian Gander not stated	Interviews. Conducted over a six year period between 2000 -2006	Researchers from organisations embedded in the community were involved so that any language issues could be minimised, though the main language of the research was English	No detail for ethical approval		Participants viewed their caring role as an extension of an existing obligation and identity. Lack of knowledge and understanding of dementia. Mistaking symptoms of dementia with old age. Carers remain isolated. Existing services seen to lack cultural awareness. Migration experiences did impact experiences of carers. Participants idealised their societies of origin, including type of support available to them in that society.	Wherever there are communities of minority elders, services should plan to identify their specific needs in discussion with community leaders, faith leaders, families and caregivers. Primary care is the first point od contact with many services for many BME elders who have often found that contact disappointing and discouraging. Cultural and language sensitivity and competence within domiciliary, day care, and institutional settings is required.

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to my study
Lawrence V Murray J Samsi K & Banerjee S (2008) Attitudes and support needs of Black Caribbean and South Asian White carers of people with dementia in the UK British Journal of Psychiatry 192 240-246 (UK)	To explore the caregiving attitudes, experience and needs of family carers of people with dementia from the three largest ethnic groups in the UK	Yes Grounded Theory	Purposive 32 carers (10 Black Caribbean 10 South Asian 12 White British) Recruitment until theoretical saturation was reached	In-depth interviews	No discussion of reflexivity	Confidentially discussed but no detail for ethical approval	Three researchers separately coded data and identified themes. These were then compared until a consensus was reached	Carers were identified as holding a traditional or non-traditional caregiver ideology according to whether they conceptualised caregiving as natural, expected and virtuous. The majority of South Asian, half of Black Caribbean and a minority of the White British participants were found to possess a traditional ideology.	Cultural attitudes suggest that specific cultural attitudes have important implications for how best to support family carers
La Fontaine J Ahuja J Bradbury N Phillips S & Oyebode J (2007) Understanding dementia amongst people in minority ethnic and cultural groups Journal of Advanced Nursing **60** (6) 605-614 (UK)	To explore the perceptions of ageing, dementia, and age related mental health difficulties amongst British People of Punjabi Indian origin	Yes	Purposive 49 participants	Focus groups	Where an Indian language was spoken the material was translated by one of the researchers	Study approval obtained from a Health Service ethics committee	Thematic analysis Inductive and deductive coding (Fereday & Muir-Cochrane 2006) Five researchers independently read and reread transcripts then compared and contrasted codes and categories	There was an implication that symptoms of dementia partly resulted from lack of effort by the person themselves and possibly lack of care by the family	There was a sense of stigma and lack of knowledge alongside disillusionment with doctors and exclusion from services

Screening questions	**Clear aim?**	**Research design appropriate to address aim?**	**Recruitment strategy appropriate?**	**How was data collected?**	**Reflexivity**	**Ethical issues**	**Data Analysis rigorous**	**clear statement of findings?**	**How valuable is the research/ relevance to my study**
Adams K (2006) The transition to caregiving of family members embarking on the dementia caregiving career Journal of Gerontological Social Work **47** 3-29 (UK)	To explore major concerns and emotions experienced by caregivers of persons recently diagnosed with Alzheimer's disease , and their thoughts about informal or formal sources of help	Phenomenology (Moustakas 1994) & Grounded theory (Strauss & Corbin 1990)	Purposive sample 20 participants	Semi structured interviews	Author had personal and clinical experience with Mildly Cognitively Impaired older adults and had done prior research on caregivers' grief and depression.	No detail for ethical approval	2 persons, author and a research assistant coded each transcript and identified themes using NVivo. Coders were not blind to one another's coding. Research assistant codes integrated into authors codes and differences resolved by the author	New tasks. Changes in relationships Negative emotions Support from family and friends	The caregiving role may be taken on very gradually and the effects on new caregivers may not be immediately obvious Many participants in this study had not disclosed diagnosis to anyone at their places of worship so these were not sources of direct support.
MacKenzie J (2006) Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK Dementia: The International Journal of Social Research and Practice **5** (2) 233-248 **(UK)**	To use findings to develop and deliver culturally appropriate support group materials for South Asian and East European family carers of relatives with dementia living in the UK	Yes	Purposive	Semi Structured interviews			Thematic analysis (Scheff (1990) framework	Insights into how understanding of dementia in different cultural contexts can become operationalised through stigma and in turn influence the ways in which people with dementia and their family engage with formal and informal support	

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to this study
Jett K (2005) Mind loss in the African American community: dementia as a normal part of aging Journal of Aging Studies **20** (1) 1-10 (US)	To explore the cultural and linguistic variations in the definition, recognition and explanation of, and response to dementia in the African American community	Grounded theory	Snowball 14 Participants who knew someone with dementia not necessary caregiver (13 women 1 man)	Semi structured interviews supplemented by observation and field notes while researcher participated in health promotion activities	No discussion of reflexivity	Approval by Institutional Review Board	Thematic Analysis Findings returned to participants for validation and clarification	The term dementia held little meaning to the participants Alzheimer's was used only by persons who had heard from a health professional and was used in a generic sense rather than to a specific condition	In framing dementia as normal aging, it becomes a non-issue. While greater access to support networks, experience of adaptation to adversity, more use of prayer and reframing are very useful in the African American community it also prevents diagnosis and treatment of dementia and some types of mental illness.
Jones R Chow T & Gatz M (2006) Asian Americans and Alzheimer's disease: assimilation, culture and beliefs Journal of Aging Studies **20** (1) 11-25 (CAN)	To understand the factors shaping attitudes towards Alzheimer's disease	Yes	Purposive	Focus Groups	The language in which each group was conducted was determined by its members and leader's preference	No detail for ethical approval	Coded and analysed using content analysis (Rosenthal & Rosnow 1991)	A picture of the obstacles to care and treatment for AD in specific Asian American populations	The scarcity of culturally sensitive healthcare practitioners
Adamson J & Donovan J (2005) 'Normal disruption': South Asian and African-Caribbean relatives caring for an older family member in the UK. Soc Sci Med **60** 37-48 (UK)	to examine the meaning of being an informal caregiver of an older family member living with dementia for South Asian and African Caribbean caregivers	Yes	Purposive and snowball 21 African Caribbean 15 South Asian	In depth semi-structured interviews	Interviewer JA did not speak any South Asian languages. Acknowledges interviews done without an interpreter were less stilted produced richer data	No detail for ethical approval	Data collection and analysis concurrent. Transcripts scrutinised and coded using comparative techniques to identify themes (Glaser & Strauss 1967 Strauss and Corbin 1994)	Caregivers described caregiving as a continuations of their previous relationship with the person being cared for and their role within the family. However participants also described highly disruptive elements to this change in relationships.	Attempts to consider the relationship between individual experiences, cultural factors and macro social structures

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to this study
Mahoney D Cloutterbbuck J Neary S & Zhan L (2005) African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of Dementia: Cross cultural similarities and differences The Gerontologist **45** (6) 783-792 (US)	African American, Chinese and Latino family caregivers' impressions of the onset and diagnosis of dementia: Cross cultural-similarities and differences	Yes A meta-analysis of three qualitative studies	Purposive 22 Caregivers (4 Chinese 11 Latino 7 African American)	Focus Group for African American caregivers Individual interviews with Latino and Chinese caregivers	African American focus group was facilitated by African American researcher who also transcribed notes Interviews conducted in Spanish and Chinese transcribed by bilingual transcriptionists	Approval from the Institution Review Board at the Hebrew Rehabilitation Centre for the Aged and the Massachusetts Executive Office of Elder Affairs All caregivers were paid $15 honorarium for participation	Lead Author read all transcripts. using Whittemore (2005) quality criteria for qualitative reviews. Original investigators affirmed coding and thematic interpretations	Yes Primary Physicians failure to recognise dementia or refer to specialists was more problematic than language or ethnic differences	This study adds to the literature that compares racially and ethnically diverse family caregivers of elders living with dementia. The three groups expressed different cultural factors that influenced their response to and actions as caregivers. African Americans noted concerns about racism, which contributed to reluctance to seek medical care. Chinese caregivers noted that stigmatisations associated with mental illness extended to dementia. Latino caregivers noted the strong natural aversion to nursing home or institutional care.
Neary S & Feany D (2005) Dementia Caregiving: the experiences of Hispanic/Latino caregivers Journal of Transcultural Nursing **16** (2) 163-170 (US)	To explore dementia caregiving in a group of Latino caregivers to identify cultural influences on the caregiving experience	Yes Leininger's ethnonursing approach	Purposive 11 caregivers (All Latino) (9 female 2 male)	In-depth semi structured interviews	No discussion of reflexivity	Approval from the Institution Review Board at the Hebrew Rehabilitation Centre for the Aged and the Massachusetts Executive Office of Elder Affairs	WinMax qualitative data analysis programme for initial coding and analysed using ethnonursing data analysis (Leininger & McFarland 2002)	Participants shared culturally related beliefs about family obligations, reciprocity and the primacy of home-based care	This study extends research on Hispanic/Latino dementia caregivers Findings suggest that underlying implicit cultural values, and the ways caregivers negotiate tension between beliefs and demands of their individual experiences

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to this study
Park M Butcher H & Maas M (2004) A thematic Analysis of Korean family caregivers experiences in making the decision to place a family member with dementia in a long term care facility Research in Nursing and Health 27 345-356 (US)	to provide and in-depth description of Korean family experiences making decision for placement of family member in a long term care facility	Yes	Purposive 19 caregivers (All Korean)	Interviews	No discussion of reflexivity		Luborsky method for thematic analysis (1994) 656 themes sorted into 17 topics to create 4 themes	Yes Trauma in making decision Apprehension, and deep sorrow most keenly felt.	This study contributes to the understanding of caregiving experiences in a country in transition from traditional society based on Confucianism to a westernise society. The results of study serving a reference by Korea Ministry of Health and Social Welfare taskforce looking at long term care facilities
Zhan L (2004) Caring for family members with Alzheimer's disease perspectives from Chinese American Caregivers Journal of Gerontological Nursing **30** (8) 19-29 (US)	To examine the experiences of Chinese American	Grounded Theory	Purposive 4 Chinese American (3 women 1 man)	Semi structured open interviews	No discussion of reflexivity	Approval from the Institution Review Board at the Hebrew Rehabilitation Centre for the Aged	WinMax qualitative data analysis programme for initial coding and in-depth description of content analysis	Educational and service outreach is first step to reducing stigmatisation of AD in the Chinese American community.	Cultural norms influence the extent to which support is available Culturally sensitive services are needed to improve access to and treatment in AD services

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to my study
Cloutterbuck J & Mahoney D (2003) African American dementia caregivers: The duality of respect Dementia **2** (2) 221-243 (US)	Yes To explore the perceptions and experiences of African American caregivers of family members with dementia	Yes	Purposive 7 caregivers (All African American) (5 women 2 men)	Focus group interviewing	No discussion of reflexivity	Approval from the Institution Review Board at the Hebrew Rehabilitation Centre for the Aged and the Massachusetts Executive Office of Elder Affairs	WinMax qualitative data analysis programme for initial coding and in-depth description of content analysis	Delay in evaluation of persons in the African American community may be caused unwittingly by the cultural tradition of respecting and protecting elders. African American families must be placed in the historical context of their ethno-cultural group.	Cultural perceptions of dementia Findings inform providers about important issues to consider when studying dementia among African American families and the legacy of mistrust of health care providers and care institutions among BAME communities
Ho B Freidland J Rappolt S & Noh S (2003) Caregiving for relatives with Alzheimer's disease: feelings of Chinese Canadian women Journal of Aging Studies **17** 301-321 (CAN)	To explore with Chinese-Canadian female caregivers their feelings about providing for relatives with Alzheimer's disease	Yes	Purposive 12 caregivers (All Chinese Canadian)	Semi structured interviews	Consent form written in both English and Chinese. Verbal explanations given in Cantonese. Interviews conducted and transcribed in Cantonese Coding spot checked by bilingual (Chinese - English) health professional	Approval from University of Toronto Ethics Committee	Analysed manually using Miles & Huberman (1984) as guide. Coded and thematic analysis in English .	Dissonance between caregivers expressed views and actual intention about institutionalisation	Underlying anxiety that their social was changing even as they played out traditional female caregiving roles

Screening questions	Clear aim?	Research design appropriate to address aim?	Recruitment strategy appropriate?	How was data collected?	Reflexivity	Ethical issues addressed	Data Analysis rigorous	clear statement of findings?	How valuable is the research/ relevance to this study
Adamson J (2001) Awareness and understanding of dementia in African /Caribbean and South Asian families Health and Social Care in the Community **9** (6) 391-396 (UK)	Explore awareness, recognition and understanding of dementia symptoms in families of South Asian and African Caribbean descent in the UK	Yes	Purposive and snowball 30 caregivers (18 African Caribbean 12 South Asian)	Semi structured interviews	Author did not speak any South Asian languages so interpreters were used for 3 participants This resulted in less rich data than might have been achieved by researchers who could interact in the language of the interviewee.	Confidentially discussed but no detail for ethical approval	Yes Transcripts were scrutinised and coded identifying themes and negative cased by the constant comparative technique of grounded theory	In the African Caribbean group while carers generally did express in some way an awareness that their relative had dementia, this contrasts with the lack of knowledge before they had a diagnosis	The process of caregivers recognising symptoms can be blurred with caregiving taking time to notice something is wrong a phenomenon well reported in the literature, but noting that minority ethnic groups less inclined to talk about it.
Lampley-Dallas V Mold J & Flori D (2001) Perceived needs of African American caregivers of elders with dementia Journal of the National Medical Association **93** (2) 47-57 (US)	To assess needs of African American caregivers and their expectations of the health care system		Purposive 13 African American caregivers	Focus groups	Facilitators of focus groups were African American	Approved by Oklahoma University Institutional Review Board	Coded by 4 individuals. Transcripts reviewed by one of the coders for themes then agreed by other three coders	Scarcity of support groups in African American community	Services an information on dementia and its management must be tailored toward demographic differences among and within ethnic and minority groups

Table 2:3 Screening of studies for methodological quality using CASP (2014)

Appendix 3

Ethics approval England

HP/EH

7th August 2012

Janet Bailey
School of Health and Wellbeing
Nursery Street
City Campus
Wolverhampton
WV1 1AD

Dear Janet,

Re: "The experiences of African- Caribbean family carers for a family member with dementia: insights from England and Jamaica"

The School of Health and Wellbeing Ethics Sub-Committee Board met on *16th July 2012* **Your project was approved without amendments**, and you now may proceed with this study.

It was agreed for your project to be awarded the following Codes.

University Category: A1- Favourable

I would like to wish you every success with the project.

Yours sincerely

H Paniagua

H Paniagua

Dr H Paniagua PhD MSc, BSc (Hons) Cert. Ed. RN RM
Chair – School Ethics Committee

Ethics approval Jamaica

SCHOOL OF GRADUATE STUDIES, RESEARCH AND ENTREPRENEURSHIP
University of Technology, Jamaica

RESEARCH ETHICS COMMITTEE

CLEARANCE CERTIFICATE

REF: **2013/HE/03/26** PROTOCOL NUMBER_____

PROJECT: *The Experiences of African-Caribbean (Jamaican) family carers caring for a family with dementia: insights from England and Jamaica*

INVESTIGATOR/S: Mrs. Janet Bailey and Professor Laura Serrant-Green, University of Wolverhampton, England

FACULTY/SCHOOL: University of Technology, Jamaica and the UWI, Mona Campus

DATE CONSIDERED: January 10, 2013

DECISION OF COMMITTEE*: **APPROVED**

CHAIRMAN'S SIGNATURE:_____ DATE: January 11, 2013

Cliff Riley, PhD

*Guidelines for written "informed consent" attached where applicable.

Supervisor: Professor Laura Serrant-Green, Centre for Health and Social care Improvement, University of Wolverhampton, UK

Ethics application University of Wolverhampton

School of Health and Wellbeing Ethics Committee: Researcher Check List

Before submitting your proposal for ethical considerations please make sure you have covered the following points.

1) Have you completed the submission document?	Yes	
2) Is your proposal no more than 1500 words?		No
3) Project Proposal included with signature from supervisor	Yes	
4) Have you included ALL the required appendices documents?		
Original letter of access and approval letter from management	Yes	
Letter to Participants	Yes	
General Consent and right to withdraw	Yes	
Participant information sheet	Yes	
5) Have you filled in all the chief investigator details as requested?	Yes	
6) Have you completed the participant recruitment section?	Yes	
8) Have you clearly addressed ALL the ethical issues relating to this research? Such as		
Confidentiality and anonymity	Yes	
Data Protection and data storage	Yes	
Coercion and Consent	Yes	
Potential emotional stress to the participant and how this will be handled	Yes	
Length of time data will be stored	Yes	
Who will act as your custodian of the data?	Yes	
Is the study going to a local REC committee if so which one?		No

*If you have answered all the above questions and the relevant documents have been included please contact the ethics secretary [redacted] at [redacted] or **call 01902518617** to arrange submission.*

Chief Investigator: Janet Bailey

Title of the Research: The Experiences of African-Caribbean family carers caring for a family member with dementia : Insights from England and Jamaica

Category: Professional Doctorate in Health and Wellbeing

Chief Investigator's Details

Forename: Janet
Surname: Bailey
Position: Senior Lecturer in Mental Health

Qualifications and Professional background:

Registered Nurse (Mental Health)
Registered Nurse (Learning Disabilities)
Graduate Diploma Mental Health Nursing
BSc Community Health Nursing
MSc Advanced Nursing Practice
LLM Mental Health Law
Post Graduate Certificate Education
Fellow Higher Education Academy

My professional background is a Registered Nurse since 1981, combined with teaching in Higher Education since 1999.

Former Chair for Birmingham Branch of the Nurses Association of Jamaica (UK).

Also an Associate Hospital Manager with a Foundation Trust and an Independent Hospital chairing hearings for renewals, appeals, and Community Treatment Orders for patients compulsorily detained under the Mental Health Act 1983 (as amended 2007).

Qualified first aider, appointed as an external assessor for West Midlands Police Service and provider of Fire and Emergency Support with the British Red Cross.

Address:
School of Health and Wellbeing
Mary Seacole Building
Nursery Street
City Campus North
Wolverhampton
Postcode: WV1 1AD
Telephone number: [redacted]
Alternative number: [redacted]
Email address: [redacted]

Director of Studies Name and contact details:

Professor Laura Serrant-Green
Director of Research and Enterprise
Centre for Health and Social Care Improvement
City Campus North
Wolverhampton
Postcode: WV1 1AD
Telephone number: [redacted]
Email address: [redacted]

Second Supervisor name and contact details

Dr Della Sadler-Moore
School of Health and Wellbeing
Mary Seacole Building
Nursery Street
City Campus North
Wolverhampton
Postcode: WV1 1AD
Telephone number: [redacted]
Email: [redacted]

How many words is your proposal?
1471 (excluding references)

Please LIST the major ethical issues you have discussed in the attached research proposal.

Ethics approval England
Ethics approval Jamaica
Informed Consent
Confidentiality, anonymity, and data protection
Support for participants
Potential problems/risk assessment for an overseas project

Declaration:

Chief Investigator Signature [redacted]

Director of Studies Signature [redacted]

Second Supervisor Signature _____

Title of the proposed research

The experiences of African-Caribbean (Jamaican) family carers caring for a family member with dementia: Insights from England and Jamaica

Background / justification for conducting the study

The central premise of this study is to seek to understand the African Caribbean (Jamaican) experience of caring for a family member with dementia. The Alzheimer's Research Trust (2010) estimates that dementia directly afflicts 820,000 people in the UK and a range of evidence (Lawrence et al, 2008; Adelman, 2009 and DH, 2009) suggests that in England family members support around two-thirds of older people with dementia. In February 2009 the government launched its first National Dementia Strategy for England and Wales (DH 2009), intended to be a catalyst for a change in the way people with Dementia are cared for as economists have stated that dementia is now costing England £10 billion per year in health and social care costs, without factoring in the current contribution of unpaid carers at an estimated cost of £12 billion per year, (Beckford –Ball 2009).

Over half, (approximately 250,000), of migrants from the Caribbean who came to England in the late 1950s and early 1960s came from Jamaica. This early group consisted largely of young couples and their children. There were few 'grandparents' in this early migrant population and those who came had little intention of staying. However, families and communities became settled and there are now a great number of these migrant Jamaicans all aging at the same time.

Dementia, particularly vascular dementia, is increasing rapidly within this aging migrant community compared to the white British born population due to known risk factors of hypertension and diabetes (Adelman 2009), and recently concern has being expressed that changes in family structure might mean fewer family carers willing to look after family members at home, which will lead to an increased propensity to admit people with dementia into care homes, (Right Care, Right Here, 2010). With the recent cost crisis exposed in one the largest UK providers for elderly residential care (Southern Cross), this concern begins to take on worrying proportions for policy makers.

In England the idea of the welfare state is so firmly embedded that there is an expectation, often perceived as a right, that the government should provide institutions and facilities to look after elderly family members. In Jamaica however, apart from certain facilities for the 'indigent poor', there are few state institutional care facilities for the elderly with long term conditions such as dementia. There is church and NGO (Non-government organisations) funded provision, but there is no expectation that their limited capacity could provide comprehensive or coordinated care, as enshrined in Jamaican law (Maintenance Act (2005) Part V 10 1) is the obligation of families to support their elderly relatives.

With such diametrically opposed positioning regarding the provision of care for elderly family members with dementia, what can be learnt from these two countries?

Purpose of the Research

The aim of this study is to explore the meaning and the essence of caring as experienced by African Caribbean (Jamaican) family carers, caring for a family member with dementia in the divergent cultural settings of England and Jamaica.

Potential Benefits arising from the Study

Potentially England and Jamaica have much to learn from each other. This study might assist in the identification of the most effective interventions, the best avenues for research and resource allocation, and frameworks for investment in, and training of, family and community carers, programmes for public education around care-giving, and accepting the role of the state and third sector in the funding, support and delivery of policy initiatives.

Research Design

This study will employ a framework of Interpretative Phenomenology (Hermeneutics). (Giorgi 1997; Todres 2005). Crotty (1996) and Paley (1997) claimed that the aim of phenomenological research is the subjective experiences of the participants, but Lopez and Willis (2004) and Dahlberg et al (2008) argue that hermeneutic phenomenological analysis goes beyond mere description of a phenomenon and looks for the essence and meaning embedded in common practices. Heidegger (1962) emphasised that it is impossible to rid the mind of the background understandings that has lead the researcher to consider the topic worthy of research in the first place, so I believe that my personal and professional knowledge, together with my and experience as a carer is both useful and necessary for this study, but heeding the cautions of Mauthner and Doucet (2003) reflexivity throughout the research process will encourage a disciplined subjectivity in managing and contextualising the data and its analysis.

Population / sample

This study will use non probability purposive sampling with the only necessary criteria that participants are over the age of 18 years, African Caribbean (Jamaican), and caring for a family member with dementia for a period of 12 months or longer. Sample size will be limited to a maximum of 10 across both countries.

During August 2012 a letter of invitation (Appendix 1) and information sheet (Appendix 2) will be available to Carers Supports groups at the Alzheimer's Society Black Country and the Alzheimer's Jamaica in Kingston. I will be available to meet potential participants in England in September 2012 and in Jamaica in November 2012 to agree and sign Consent Forms (Appendix 3).

Data collection method(s)

This study will involve a narrative approach to capture the family carers' experiences and perspectives using phenomenological interviews, open ended questions and prompts (Denscombe 2007), as a way of encouraging participants to reveal themselves. McCance et al (2008) recommend starting with a broad descriptive

question intended to place the interview in the context of the participants lived experience before moving on to more focused, open ended probing questions to enrich the description. Final data collection tool will be finalised from initial literature review but a draft interview schedule is attached, (Appendix 4)

Interviews will be timed to last no more than one hour and with participants' permission, will be audio taped using a digital recording device and transcribed verbatim.

Although English is the official language in Jamaica, and the participant information and consent forms will be produced in English, Jamaican patois is spoken extensively throughout the island so translated and audio versions will also be made available.

As I am a Jamaican by descent who speaks and understands Jamaican patois, there will be no issues affecting the viability and validity of data collection or transcription.

Pilot

Data collection tool will be finalised from initial literature review, but a draft schedule is attached (Appendix 4) and the recording and transcript of a practice interview will be shared with Supervisors.

Analysis of Data

Interviews will be analysed using steps proposed by Giorgi (1997) as summarised by Smith et al (2009). (Appendix 5)

Ethical considerations

No legal risks or liabilities are envisaged in conducting this study. This study has been granted assess and support from the Dean at the School of Health and Wellbeing University of Wolverhampton (Appendix 6) and the Associate Dean at the College of Health Sciences, University of Technology, (UTech) Jamaica (Appendix 7).

Potential participants in both countries will be sent (via a Carers Group) a letter of invitation during August 2012 to become involved (Appendix 1), together with information (written and audio) (Appendix 2), explaining the study, and a Consent Form (Appendix 3) to complete if they wish to be part of study. I will meet with potential participants, (in both countries) during October/November 2012 to complete consent forms.

It is planned that all interviews will be conducted during the daytime at pre-booked times and locations in conjunction with the Alzheimer's Organisations in England and Jamaica. Other locations that may be convenient for participants, particularly those living in the more rural parts of Jamaica will be risk assessed and accessed if suitable, and support for this was secured with Alzheimer's Jamaica during visit to Jamaica in April 2012.

Confidentiality will be maintained in this study by not divulging information to anyone other than those persons directly involved in the study, ie.my research supervisors in England and Jamaica. No-one other than myself will be able to link the interview recordings or notes to participants as the data will be anonymised using codes on all interview notes and transcripts. Any quotes used when writing up the research will use a pseudonym rather than the participant's name. Data will be protected by the electronic uploading of interview recordings and transcripts to a secure server at the University of Wolverhampton avoiding the physical transit of any data. Once the study has been examined all audio and notes will be destroyed when advised by research supervisors.

I am aware that in discussing their experiences there is the potential that carers may become distressed. As an Registered nurse for over 30 years, with extensive mental health experience and the knowledge of being a carer myself for many years for my mother who had dementia I am able to recognise and react appropriately if a participant becomes distressed, and I am have ensured that all participants will be recruited through and have access to on-going support of a Carers group with the Alzheimer's organisations in England and Jamaica.

Research base whilst in Jamaica will be the College of Health Sciences at UTech in New Kingston. I am familiar with Jamaica and the university campus but first point of contact in the event of any adverse incident would be the Dean, Dr Ellen Campbell-Grizzle followed by contact with my research supervisors Professor Denise Eldemire-Shearer (Jamaica) or Professor Laura Serrant-Green (England).

Should this study have to stop prematurely for any reason, I or my research supervisors would contact participants through the respective Alzheimer's Organisation Carers Group with an explanation.

On successful completion, the results of this study will be published as part of my Professional Doctorate in Health and Wellbeing at the University of Wolverhampton, and journals in England and Jamaica. If participants would like me to send them copies of any publication I would be happy to do so. This study will also be discussed at conferences in England and Jamaica and participants will be invited to attend, (and take part if they wished to).

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Appendices.

1) **Invitation letter to participants**
2) **Participants information sheet**
3) **Consent form**
4) **Draft interview schedule**
5) **Data analysis**
6) **Access and approval Dean England**
7) **Letter of support Associate Dean Jamaica**
8) **Ethics application/approval from Jamaica**

Appendix 1
Invite letter to participants

Will be on headed paper with University logos

Dear

I am writing to invite you to participate in a research project, which I am conducting as part of a Professional Doctorate degree in Health and Wellbeing at the University of Wolverhampton - England. I enclose an information sheet, which explains the title and aims of my project.

If you are willing to be interviewed, the interview would take no longer than 50 minutes. Anything you say would be totally confidential and any notes made as a result of the interview would be destroyed afterwards. The interview would here at the University or at another venue that is convenient for you. A report will be written of the findings but numbers will replace all names so that you cannot be identified.

If you feel that you would like to be interviewed please indicate this on the attached Consent Form and send back to me in the attached envelope, and I will be happy to meet with you to answer any questions you may have before taking part.. If you would prefer not to be involved, please destroy this letter.

If you decide not to be involved I would like to assure you that your support and care will not be affected in any way.

Yours sincerely,

Janet Bailey LLM MSc BSc PGCE RMN RNLD FHEA
Senior Lecturer

Appendix 2
Participant Information Sheet (Draft 3: 17 April 2012)

The experiences of African-Caribbean (Jamaican) family carers caring for a family member with Dementia: Insights from England and Jamaica

Greetings,

My name is Janet Bailey. I am a Nurse and Senior Lecturer at the University of Wolverhampton in England, and I am inviting to you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information and feel free to discuss it with friends and relatives. Please contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you in advance for reading this.

What is the purpose of the study?

The purpose of this study is to gain an understanding of the experience of African-Caribbean (Jamaican) family carers caring for a family member with Dementia.

Dementia is increasing rapidly in England within the aging migrant African-Caribbean (Jamaican) community (Adelman 2009). Over half the West Indians who came to England in the late 1950s and early 1960s came from Jamaica. We know that there is an increased risk of dementia, (particularly vascular dementia), in African-Caribbean people compared to the white British born population due to known risk factors of hypertension and diabetes, (Adelman 2009).

Currently in the UK around two thirds of older people with dementia are supported or cared for by family members, and this is especially true of African-Caribbean (Jamaican) families who are less likely to access specialist health and social care services. In England the welfare state is so firmly embedded that for many there appears to an expectation, almost a right, that there will be institutions and facilities to look after elderly family members.

Concern has being expressed that changes in family structure might mean fewer family carers willing to look after family members at home, which will lead to an increased propensity to admit people with dementia into care homes, (Right Care, Right Here Programme 2010), and with the recent cost crisis exposed in one the largest UK providers for elderly residential care (Southern Cross),this concern begins to take on worrying proportions for policy makers.

In Jamaica, there are 250,000 elderly people (approximately 10% of the population), and Jamaica has had a National policy for Senior Citizens since 1997). In Jamaica, apart for certain facilities that have mainly existed for the indigent poor there has never been any institutional care facilities set up for the elderly. In recent discussion with a senior academic colleague at the University of the West Indies who is the advisor to the Jamaican government regarding the care of its elderly persons, it was stressed that institutional care is not a model of care that anyone would like to see introduced in the Caribbean.

So, can we learn from each other in England and Jamaica anything that might help to identify effective interventions to focus resources for investment and training with family carers, who in both countries remain central to the care of people with dementia?

Why have I been chosen?

You have been sent this invitation because you have been identified as carer who has been caring for family member with dementia for more than 12 months and you have had contact with a Carers Group at the Alzheimer's Organization in England or Jamaica.

I am intending to only speak with a maximum of 10 families across England and Jamaica.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care or support you receive.

If you do decide to take part a copy of this Information Sheet and the signed consent form attached will be given back to you to keep.

What will happen to me if I take part?

To take part all that is required of you is one interview, with just me, that should last no more than 50-60 minutes.

What do I have to do?

All you have to do is talk about your experiences of caring for your family member who has dementia.

A meeting would be arranged at time that is convenient to you and would take place at a location where you would normally attend for a Carers meeting in England or Jamaica, or at your home address if you live in a rural area 'country' in Jamaica.

With your permission I would like to record our meeting on a digital recorder. Notes of what you say will be made available for you, and I assure you that other than me, just my research supervisors will have any assess to them. Any quotes used when writing up the research will not use your name, and all recordings and notes will be destroyed when this study is complete.

What are the possible benefits of taking part?

The aim of this study is to explore the essence of caring as experienced by African-Caribbean family carers in the divergent cultural settings of England and Jamaica. Potentially England and Jamaica have much to learn from each other.

What will happen to the results of the research study?

The results of this study will published as part of my Professional Doctorate in Health and Wellbeing and journals in England and Jamaica. If you would like me to send you copies any publication I would be happy to do so. This study will also be discussed at conferences in England and Jamaica that you will be invited to attend and take part if you wanted to.

Who has reviewed the study?

This study has been reviewed by the University of Wolverhampton (England), the University of Technology (Jamaica) and the University of the West Indies (Jamaica).

Appendix 3
Consent Form

Will be on University of Wolverhampton headed paper

CONSENT FORM AND RIGHT TO WITHDRAW

Title of Project: The experiences of African-Caribbean (Jamaican) family carers caring for a family member with dementia

Name of Researcher: Janet Bailey

Please initial boxes

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the above study. ☐
4. I understand that the researcher may wish to publish this study and any results found, for which I give my permission ☐
5. I agree for this to be tape recorded and for the recording to be used for the purpose of this study. ☐

.....	.....	.....
Name	Date	Signature
.....	.....	.....
Researcher	Date	Signature

Appendix 4
Draft interview Schedule

Appendix 6
Access and Approval
Dean - School and Health and Wellbeing
University of Wolverhampton England.

UNIVERSITY OF
WOLVERHAMPTON
KNOWLEDGE • INNOVATION • ENTERPRISE

Professor Linda Lang PhD
Dean of the School of Health and Wellbeing

Mary Seacole Building
Nursery Street
City Campus North
Wolverhampton WV1 1AD
United Kingdom

Telephone Codes
UK: 01902 Abroad: +44 1902

Switchboard: 321000
Fax: 518660

Internet: www.wlv.ac.uk/shaw

☏ 01902 518624
Fax: 01902 518660
Email: [redacted]

Our Ref: LL/df

Date: 22 March 2012

Ms Janet Bailey
Senior Lecturer
Mental Health
School of Health and Wellbeing
University of Wolverhampton

Dear Janet

Thank you for your letter of 19 March and attachment. Subject to Ethical Approval, I am happy for you to undertake your study with the School of Health and Wellbeing.

The topic is obviously very interesting and therefore, I would really like to know about your findings. If you could towards the end of the study get in touch to give me some feedback that would be very useful.

I wish you every success in your project.

Best wishes,

Yours sincerely

[redacted]

Professor Linda Lang
Dean – School of Health and Wellbeing

Appendix 7

Letter of Support
Associate Dean - Graduate Studies and Research
College of Health Sciences University of Technology (UTech) Jamaica

University of Technology, Jamaica

237 Old Hope Road, Kingston 6
Jamaica, West Indies
Phone (876) 927-1650-6
Fax (876) 977-4258
Website www.utechjamaica.edu.jm
E-mail registrar@utech.edu.jm

President: Professor the Hon. Errol Morrison
OJ, MD, PhD, FRCP (Glasg), FACP
FRSM (UK), FRSH

May 2, 2012

Mrs. Janet Bailey
Senior Lecturer
University of Wolverhampton
School of Health and Wellbeing (SHaW)
Mary Seacole Building
Nursery Street
City Campus North
Wolverhampton WV1 1AD

Dear Mrs. Bailey,

RE: Visit to the University of Technology, Jamaica

We wish to extend to you our appreciation for considering the College of Health Sciences, University of Technology, Jamaica (UTech) as a collaborator on your Research Project. The discussions held between you, Professor Hewitt (Associate Dean, Nursing), Ms. Beverly King (Head, Caribbean School of Nursing) and I at our April meeting were very informative and encouraging. As outlined by the team, we believe that the project is timely, relevant and very appropriate. In addition to this, we are more than happy to assist in whatever way possible to ensure timely and successful completion of your project objectives.

In order for these objectives to be met in a timely manner we believe that you should consider having further dialogue with Professor Eldermire-Shearer, Head, Department of Community Health, University of the West Indies, Mona as her expertise and access to the target population will contribute greatly to the quality and timely completion of your project. As it relates to the

ethic procedures, you may have to seek ethical clearance from the University Hospital of the West Indies (access patients from the UHWI), The South Eastern Health Authority (SERHA- for access to patients in Kingston) and the University of Technology, Jamaica (Collaborating institution). Please find attached copy of the University of Technology's, Ethics Application form for completion and submission. The completed form, signed by your principal research supervisor, should be submitted directly to my office accompanied by a copy of your research proposal (inclusive of the data collection instrument and informed consent form).

Thank you again for choosing the College of Health Sciences, University of Technology, Jamaica. Your interest in partnering with us is highly appreciated.

Kind Regards

Cliff Riley, PhD
Associate Dean, Graduate Studies and Research
College of Health Sciences

Ethics application University of Technology (Utech) Jamaica

SCHOOL OF GRADUATE STUDIES, RESEARCH AND ENTREPRENEURSHIP (SGSRE)
University of Technology, Jamaica

Exts: 3204/3139/3124 Email: sgsre@utech.edu.jm

Application for the Ethics Approval of Research Involving Human Subjects

1. SHORT TITLE OF PROJECT (limit 150 characters-see Guidelines)

The experiences of African-Caribbean (Jamaican) family carers caring for a family member with dementia: insights from England and Jamaica

2. APPROVAL FROM ANOTHER ETHICS COMMITTEE

Has this project been submitted (or will it be submitted) to another Ethics Committee for approval? **Yes** ☒ No ☐

If YES, name the committee(s), and give the status of each application.
(Attach copies of correspondence with each Sub-Committee)

Name of Ethics Committee and Institution	Application Reference No.	Approved/Pending/Rejected/ To be re-submitted (select one)
University of Wolverhampton School of Health and Wellbeing Mary Seacole Building City Campus North Wolverhampton WV1 1AD England		**Pending**

3. PRINCIPAL SUPERVISOR

Name: Title/first name/family name	**Professor Laura Serrant-Green**
Qualifications & position held:	**PhD MA RGN PGCE Director of Research and Enterprise/ Professor of Community and Public Health Nursing**
Organizational unit & mailing address:	**University of Wolverhampton Centre for Health and Social Care Improvement ML Building Deanery Row Off Molineux Street Wolverhampton WV1 1DT England**
Telephone	**+44 (0** [redacted]
Fax:	**+ 44(0** [redacted]
Email address:	[redacted]

4. STUDENT RESEARCHERS (Postgraduate only)

Name: Title/first name/family name	**Mrs Janet Bailey**
Qualifications:	**MSc LLM BSc RMN RNLD PGCE**
Organizational unit & mailing address:	**School of Health and Wellbeing** **University of Wolverhampton** **Mary Seacole Building** **City Campus North** **Wolverhampton** **WV1 1AD** **England**
Telephone:	**+44** [redacted]
Fax:	**+44** [redacted]
Email address:	[redacted]

5. STUDENT RESEARCH (Undergraduate)

Is this a final year project of a student of the University of Technology, Jamaica?

Yes ☐ **No** ☒

If YES, complete the following:

	Student ID No: _____
Name of student:	
Course of study:	
Research Supervisor:	

6. ESTIMATED DURATION OF PROJECT

This is the period during which you anticipate contact with participants, their personal records, or the handling of human tissue samples.

From August 2012 to August 2013

7. FUNDING

Is the project the subject of an application for funding to an internal or external grants body drug company, etc? Yes ☐ **No** ☒

If YES, answer the following questions:

(a) List the funding sources and give the status of each application.

(b) (Attach copies of the primary application for funding)

Funding Body	Approved/Pending/Rejected/To be submitted

(b) What is the exact project title on the funding application(s)?

8. PRIVACY LEGISLATION

Does the project involve access to personal information held by a Government department or agency, or private sector organization?
Yes ☐ **No** ☒

If YES, will the access to personal information be **without** the consent of the individual(s) to who the information relates?
Yes ☐ **No** ☒

If YES, to both of the above, specify the type of data to be accessed/collected, the departments/agencies holding the information, and the number of records involved.

Type of Data:
Department/Agency:

9. AIMS AND SIGNIFICANCE OF PROJECT

Provide aim(s) of the study and the potential merit(s)/significance of the study.

Aim:
To explore the meaning and essence of care as experienced by African-Caribbean (Jamaican) family carers caring for a family member with dementia in the divergent cultural settings of England and Jamaica.

Significance of the Study:
Over half, (approximately 250,000) of the migrants from the Caribbean who came to England in the late 1950s and early 1960s came from Jamaica. This early group consisted largely of first generation young migrants and their children; there were few 'grandparents'. Dementia (particularly vascular dementia) is increasing rapidly within this aging migrant community compared to the white British born population due to known risk factors of hypertension and diabetes (Adelman 2009), and it has been postulated, that with changes in family structure this might mean fewer family carers willing or able to look after relatives with dementia at home which in turn this might lead to increased care home admissions, as domiciliary care becomes less and less viable (Right Care, Right Here, 2010).

In England the idea of the welfare state is so firmly embedded that there is an expectation, often perceived as a right, that the government should provide institutions and facilities to look after elderly family members. In Jamaica however, apart from certain facilities for the 'indigent poor', there are few state institutional care facilities for the elderly with long term conditions such as dementia. There is church and NGO (Non-government

Organisations) funded provision, but there is no expectation that their limited capacity could provide comprehensive or coordinated care.

Potentially England and Jamaica have much to learn from each other. A comparative study might assist in the identification of the most effective interventions, the best avenues for research and resource allocation, and frameworks for investment in, and training of, family and community carers, programmes for public education around care-giving, and accepting the role of the state and third sector in the funding, support and delivery of policy initiatives regarding dementia.

10. SPECIFIC TYPES OF RESEARCH

Does the proposed research involve any of the following?

		Yes	No
A.	People with an intellectual or mental impairment, temporary or permanent?	☐	☒
B.	People highly dependent on medical care, e.g. emergency care, intensive care, neonatal intensive care, terminally ill, or unconscious?	☐	☒
C.	Particular communities or groups such as convicts and captive groups?	☐	☒
D.	Use of human tissue samples, features, embryos and stem cells or cell lines?	☐	☒
E.	Other specific cultural, ethnic or indigenous groups?	☒	☐
F.	Assisted reproductive technology?	☐	☒
G.	Epidemiology research?	☐	☒
H.	Human genetic research?	☐	☒
I.	Any concealment or covert observations?	☐	☒
J.	Clinical trials	☐	☒
K.	Minors under the age of 18	☐	☒

NOTE: If YES, provide details (total number involved), of how consent will be obtained. Informed consent of parents or guardians and where practical of children should be obtained in research involving children.

Number Involved:
Up to 5 (adult) carers
Informed Consent:
Consent Form (Appendix 1) which will be gained by sending a letter and an information leaflet about this study in August 2012, (Appendix 2 & 3), and meeting with Carers Groups in Jamaica November 2012.

F. How much time will potential participants have to consider the invitation to participate?

Up to eight months

G. How will potential participants be selected? *(Describe sampling method(s) to be used).*

Non-probability purposive sampling

H. How many participants will be recruited and what is the rationale for that number?

Up to 5 families. There are currently only two Carer Support groups in Jamaica for families caring for a relative with dementia; one based in Kingston and the other Mandeville, so accepting the potential limitation of access, up to 5 families is the envisioned number at this time.

I. What is required of participants? *(Attach copies of any survey, interview schedule, data sheets, etc., to be used).*

To meet with me to talk about their experience as a carer. Interviews will be timed to last no more than one hour. Interview Schedule will be finalised from initial literature review but a draft interview schedule is attached (Appendix 4)

J. How will the privacy of the participants be protected?

Interviews will conducted in a private location, with only one family carer present at any one time. I will be the only person able to link the interview recordings or notes to participants as the data will be anonymised using codes on all recordings and transcripts. Transcribed notes from interviews will be made available to individual participants to verify and other than me, just my research supervisors will have any assess to them.

Any quotes used when writing up the research will use a pseudonym, and all recordings and notes will be destroyed when the study is complete.

12. RELEVANT EXPERIENCE OF RESEARCHERS

A. Have you conducted a similar type of protocol/survey before?
Yes ☐ **No ☒**

B. When? (Please state): _____

C. Where? (Please state): _____

13. DATA MANAGEMENT

Briefly explain the ways in which you propose to ensure proper management or safety of data and findings.

Data and will be protected by regular electronic uploading of interview recordings and transcripts to a secure server at the University of Wolverhampton and avoiding as far as possible any physical transit.

14. ANALYSIS

Explain how information you receive will be analysed, interpreted and reported. What specific approaches or techniques (statistical or qualitative) will be employed?

Interviews will be analysed using steps proposed by Giorgi (1997) as summarised by Smith et al (2009) (Appendix 5)

15. PROPOSED REVIEW OF PROGRESS, PARTICIPANT CARE, AND WINDING UP PROCEDURES

Describe the mechanisms that will be put in place with the following:

Review of progress of project

Research supervision is being undertaken in England by Professor Laura Serrant-Green and Dr Della Sadler-Moore of the University of Wolverhampton and in Jamaica by Professor Denise Eldemire-Shearer of the University of the West Indies. Regular updates of progress will be provided by written report and face to face meetings.

Duty of care to participants and research staff

It is planned that all interviews will be conducted during the daytime at pre-booked times and locations in conjunction with the Alzheimer's Organisations in England and Jamaica. Other locations that may be convenient for participants, particularly those living in the more rural parts of Jamaica will be risk assessed and accessed if suitable, (and support for this has been secured with Alzheimer's Jamaica).

As a Registered Nurse since 1981, having over 20 years' experience working in mental health, and having been a carer myself caring long term for my mother with dementia, I am aware that in discussing lived experiences there is the potential that a carer may become distressed and need access to further support. To minimise the impact of this I am recruiting participants through the Alzheimer's organisations in England and Jamaica, to ensure that appropriate support and/or counselling is available for any participant who may require it.

Procedures for reporting adverse events

No legal risks or liabilities are envisaged in conducting this study.

Research base whilst in Jamaica will be the College of Health Sciences at the University of Technology (UTech) in New Kingston, and first contact would be the Dean, Dr Ellen Campbell-Grizzle, followed by contact with research supervisor(s).

Premature cessation (termination) of project

Myself, or my research supervisors would contact participants with an explanation.

Feedback of results to participants

The results of this study will published as part of my Professional Doctorate in Health and Wellbeing for the University of Wolverhampton, and journals in England and Jamaica. If participants would like me to send copies of any publication I would be happy to do so. This study will also be discussed at conferences in England and Jamaica that participants will be invited to attend (and take part in if they wished to).

I hereby declare that:
I have read and understand the University's Policy regarding human ethics. All personnel involved have adequate experience and training to perform the protocols. I will adhere to all protocols described in this document and report any modifications for the approval of the Research Ethics Committee.

Applicant's Name	Signature	Date
[redacted]	JANET BAILEY	11 July 2012.

I have read the applicant's proposal and I support the request for research ethics clearance.

Supervisor's Name	Signature	Date
PROF. LAURA SERRANT-GREEN	[redacted]	11/7/12.

Official Use Only

Decision: Approved ☐ Not Approved ☐

Chairman, Research Ethics Committee Date

Revised: January 11, 2009

Distress Protocol for qualitative data collection

Professor Carol Haigh

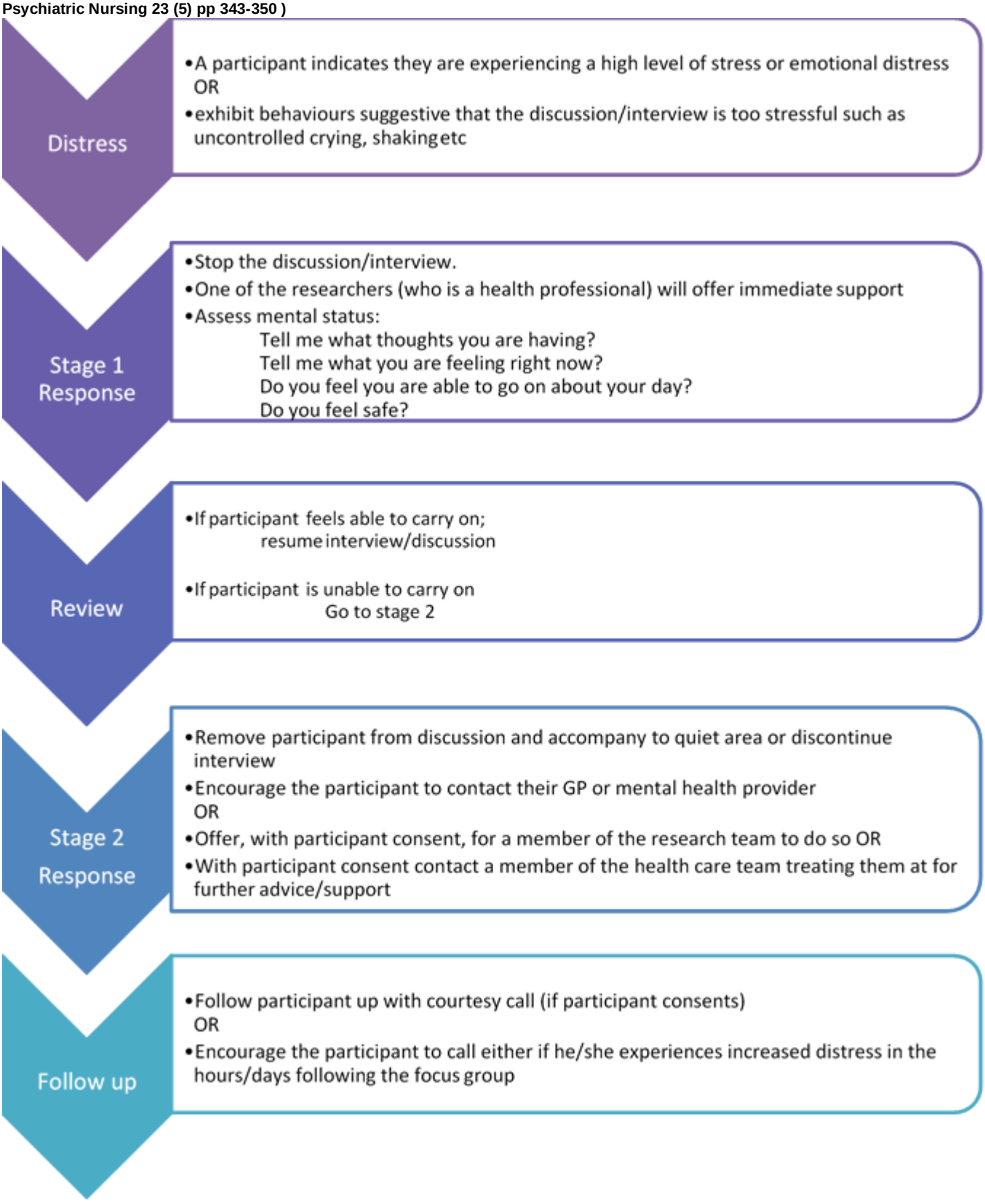
&

Gary Witham

Department of Nursing MMU

Review date 2015

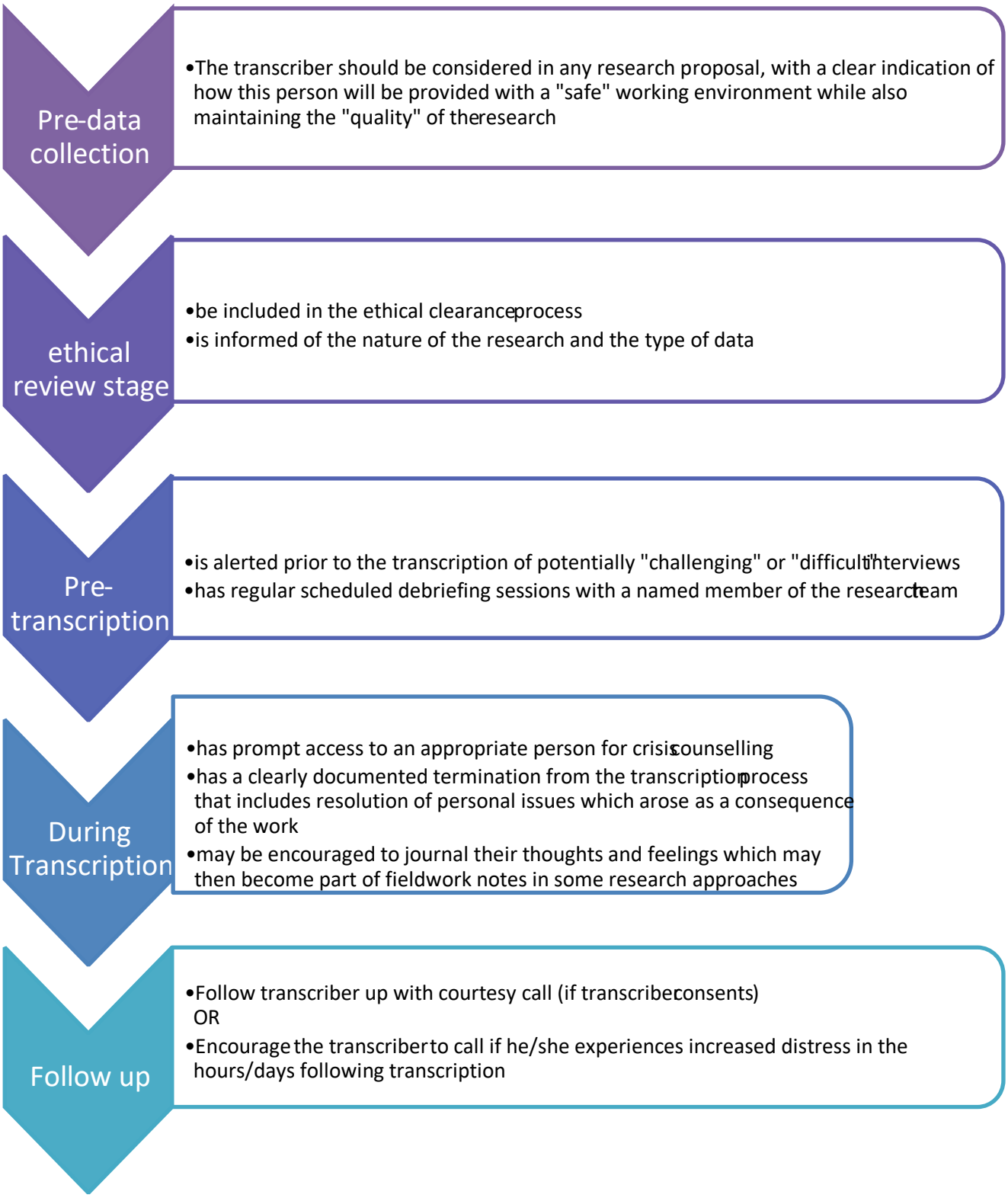
Distress Protocol 1:The protocol for managing distress in the context of a research focus group /interview (Modified from : Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. Archives of Psychiatric Nursing 23 (5) pp 343-350)



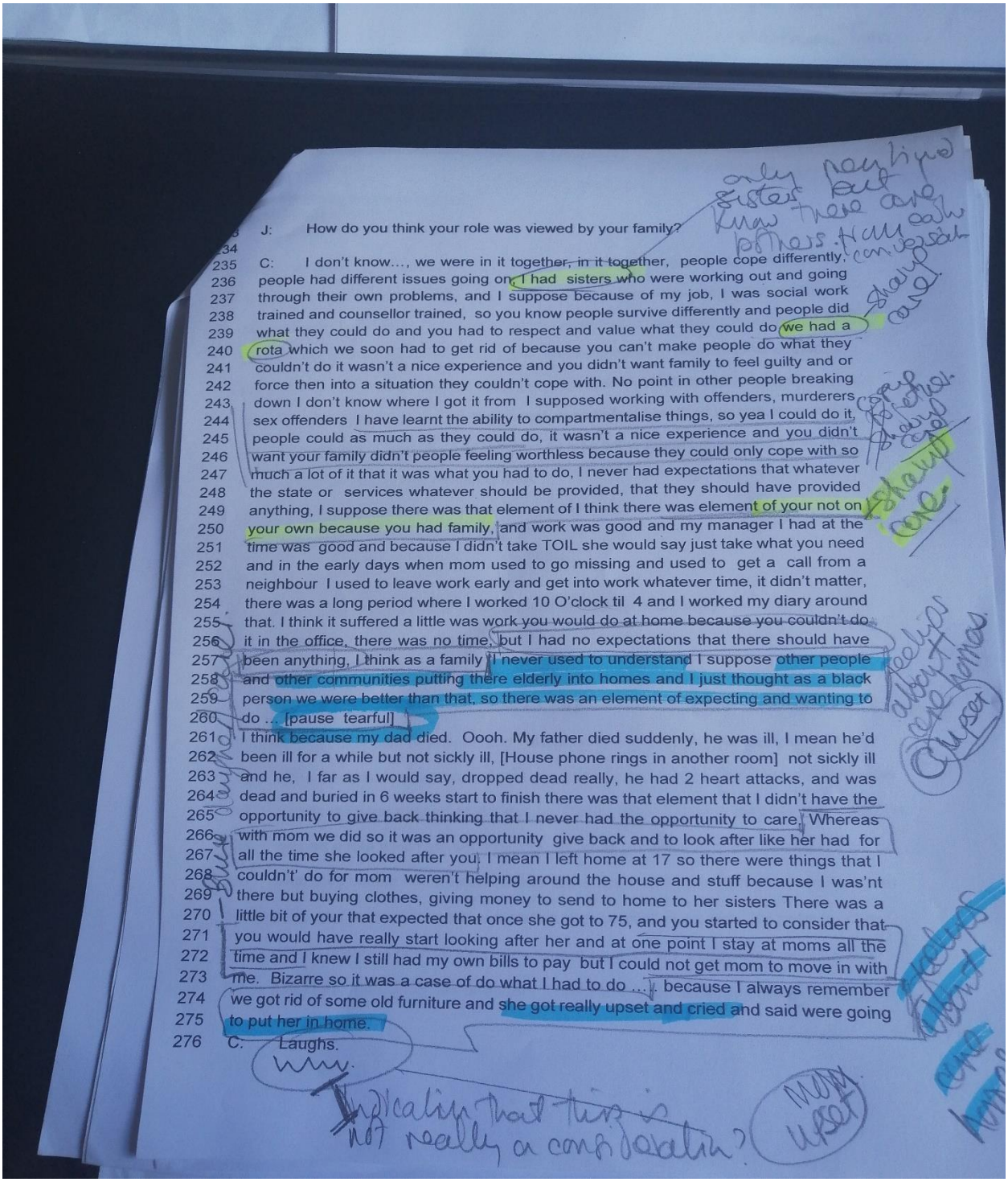
Distress Protocol 2: The protocol for managing distress in the context of a research focus group /interview management

McCosker,H Barnard, A Gerber, R (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All. Forum: Qualitative Social Research, 2(1)

Distress Protocol 3: The protocol for managing distress in the context of a research focus group /interview transcription Gregory, D Russell, C Phillips, L (1997). Beyond textual perfection: transcribers as vulnerable persons. Qualitative Health Research, 7(2), 294-300.)



Transcribe record of an interview (Part example)



J: How do you think your role was viewed by your family?

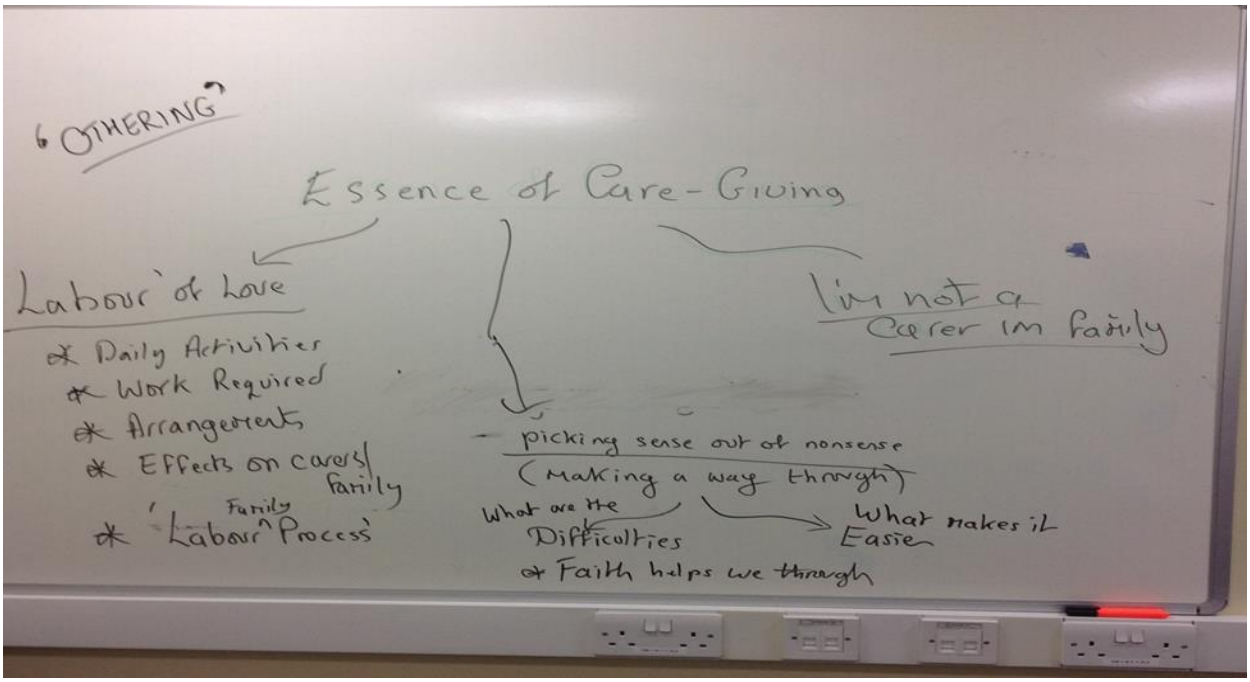
C: I don't know…, we were in it together, in it together, people cope differently, people had different issues going on, I had sisters who were working out and going through their own problems, and I suppose because of my job, I was social work trained and counsellor trained, so you know people survive differently and people did what they could do and you had to respect and value what they could do we had a rota which we soon had to get rid of because you can't make people do what they couldn't do it wasn't a nice experience and you didn't want family to feel guilty and or force then into a situation they couldn't cope with. No point in other people breaking down I don't know where I got it from I supposed working with offenders, murderers sex offenders I have learnt the ability to compartmentalise things, so yea I could do it, people could as much as they could do, it wasn't a nice experience and you didn't want your family didn't people feeling worthless because they could only cope with so much a lot of it that it was what you had to do, I never had expectations that whatever the state or services whatever should be provided, that they should have provided anything, I suppose there was that element of I think there was element of your not on your own because you had family, and work was good and my manager I had at the time was good and because I didn't take TOIL she would say just take what you need and in the early days when mom used to go missing and used to get a call from a neighbour I used to leave work early and get into work whatever time, it didn't matter, there was a long period where I worked 10 O'clock til 4 and I worked my diary around that. I think it suffered a little was work you would do at home because you couldn't do it in the office, there was no time, but I had no expectations that there should have been anything, I think as a family I never used to understand I suppose other people and other communities putting there elderly into homes and I just thought as a black person we were better than that, so there was an element of expecting and wanting to do … [pause tearful]

I think because my dad died. Oooh. My father died suddenly, he was ill, I mean he'd been ill for a while but not sickly ill, [House phone rings in another room] not sickly ill and he, I far as I would say, dropped dead really, he had 2 heart attacks, and was dead and buried in 6 weeks start to finish there was that element that I didn't have the opportunity to give back thinking that I never had the opportunity to care, Whereas with mom we did so it was an opportunity give back and to look after like her had for all the time she looked after you, I mean I left home at 17 so there were things that I couldn't' do for mom weren't helping around the house and stuff because I was'nt there but buying clothes, giving money to send to home to her sisters There was a little bit of your that expected that once she got to 75, and you started to consider that you would have really start looking after her and at one point I stay at moms all the time and I knew I still had my own bills to pay but I could not get mom to move in with me. Bizarre so it was a case of do what I had to do … because I always remember we got rid of some old furniture and she got really upset and cried and said were going to put her in home.

C: Laughs.

Searching for codes

Identifying themes



Appendix 4

Summary of findings mapped against research aim and objectives

Aim: To explore the lived experience of dementia caregiving by women of Jamaican heritage living in England and Jamaica.

Objectives:
1. To explore the experiences of family caregivers in England and Jamaica
2. To explore influences that impact on family caregivers' ability to provide care and cope with their role
3. To explore the expectations of family caregivers for long term care provision for their elders

Theme	**What is this theme about?**	**Examples from data that illustrate how participants spoke about this**	**Which research objective does this address?**	**How is this represented in the literature – does it Agree Disagree Add another dimension**	**How does this relate to wider health and social care agendas re: Policy Practice Education**
1 Strength and Resilience	Narratives described Jamaicans as proud people whose identity is associated with strength Overwhelming sense that cultural identity impacted positively on participants Faith	"Jamaicans are strong" "a strong woman who lived life on her own terms" "a hardworking woman" "I'll just do what I need to do for however long I need to do it" "We educated and have big job … but God will help us "Mom was a strong proud woman of God"	1 2	Downs (2000) influence of cultural factors. Findings add Griffith & Grolnick (2013) Research on Caribbean families. Findings add - connection between how participants raised and how they coped with challenges of caregiving Lampley-Dallas (2001) Cox (2007) Botsford et al. (2011) Valdez (2013) Similar to these studies findings suggest resilience and need to adapt to cope is instilled from childhood Duggerley et al. (2009) Shim et al. (2013) Drawing strength from past challenges Findings agree Adamson & Donovan (2005) Faith was part of the context in which participants understood and experienced dementia and a source of healing and strength Findings agree Cloutterbuck & Mahoney	This relates to policy and education Ethnic and cultural identity as Jamaicans shown to have a powerful and positive influence on caregivers' capacity to cope. For them it links their individual, family and national identities with the will the survive all challenges. Use of terms BAME and African Caribbean in health research obscures this.

				(2003) Argue that religion not important for caregivers Findings disagree Windle (2011) factors that impact on resilience building. Findings add – network supported resilience - participants mobilising significant cultural and social capital	
Theme	**What is this theme about?**	**Examples from data that illustrate how participants spoke about this**	**Which research objective does this address?**	**How is this represented in the literature – does it** **Agree** **Disagree** **Add another dimension**	**How does this relate to wider health and social care agendas re:** **Policy** **Practice** **Education**
2 A labour of love	This theme revealed that in spite of sometimes very challenging situations in managing changed behaviours of their relative there was a willingness to fulfil expectation that family member would be cared for at home even if residential care facilities might be available	"I do everything" Manage incontinence Deal with parent hoarding rubbish Going out and getting lost "Have to protect them… you know people take advantage even stealing money if they see them out at the bank or shopping" "Husband, children, job responsibilities … lots of juggling" "just adapt to a new lifestyle"	1 2 3	Dunn et al. (2002) Rader et al.. (2006) support with ADL for persons living with dementia Findings agree – physically and emotionally demanding for care recipients and caregivers Lawrence et al. (2008) Miesen & Jones (2005) Care no matter how onerous Maintaining dignity Findings agree Gottlieb & Wolfe (2002) coping responses needed to be used long enough to exert meaningful responses. Findings add another dimension- is this just an experience of the Windrush generation of new caregivers?	This relates to policy and practice Families are persevering through difficulties and pursuing support despite being denied access to specialist services, enabled by family help, and support from the church.

Theme	What is this theme about?	Examples from data that illustrate how participants spoke about this	Which research objective does this address?	How is this represented in the literature – does it Agree Disagree Add another dimension	How does this relate to wider health and social care agendas re: Policy Practice Education
3. Picking sense out of nonsense	This theme was captured in the narratives of participants bewilderments of sophisticated 21st century health and social care systems that seemed incapable of dealing with a person living with dementia. Participants expressed bewilderment that with so much purported research, training, and dementia friendly services a GP or hospital appointment was such an ordeal, and unhelpful.	"GP/Primary physician not helpful at all" "No information" "Not referred to any specialist" "finding out there is no cure" "Word of mouth - called ……. for help" "Only other families in same situation really want to talk and even begin to understand"	**1** **2**	Mahoney et al. (2005) Mukadam et al... (2011) Werner et al. (2014) Mukadam et al. (2015) Exploring how caregivers access health services. Difficulty getting family members to GPs or reporting concerns Negative experiences Findings agree Moriarty et al. (2011) Botsford et al. (2012) Mukadam et al. (2015) Getting information and understanding dementia while wanting to keep hide the vulnerabilities that arose from dementia for as long as possible Mahoney et al. (2005) McKenzie (2006) Zhan (2004) Ho et al. (2003) Findings agree	This relates to practice and education. (Nazroo 2003) Access to primary care is compounded by anticipatory fears of discrimination and previous negative experiences of services and service providers (Dilworth-Anderson et al. (2002) Participants making choices about the services they use and balancing the need for support against maintaining dignity of elders. Eldemire-Shearer et al. (2017) There is a need, highlighted in Jamaica, for primary physicians to be more aware that memory loss may not just be attributed to ageing and to adopt more use of MMSE as a screening tool to indicate when further investigation is needed.

Theme	What is this theme about?	Examples from data that illustrate how participants spoke about this	Which research objective does this address?	How is this represented in the literature – does it Agree Disagree Add another dimension	How does this relate to wider health and social care agendas re: Policy Practice Education
4 I 'm not a carer- I'm family	This theme was captured by participants resistance to identify with the term carer, instead seeing their role totally as a natural extension of their familial relationship with the care recipient	"I'm not a carer- this is my Mom" "If not me, then who?" "Once a man twice a child… that's how life goes isn't it …same way we need someone to protect and care for us at the start, same way when we get old" "I'm now the family heartbeat" "… family …everyone tries to do their part to help"	**1** **2**	Calderback (2000) Harding and Higginson (2001) Adamson and Donovan (2005) Moriarty et al. (2001) Townsend & Godfrey (2001) Molyneau (2011) Kinship caring, familial duty, and obligation BAME communities not relating to the term carer. Findings agree	This relates to policy and practice Milne (2003) Recognising how this contributed to underrepresentation of BAME communities in national assessments of the extent of caregiving. Respecting and supporting families instead of developing and promoting payments, and services that often remain under underutilised.
Theme	**What is this theme about?**	**Examples from data that illustrate how participants spoke about this**	**Which research objective does this address?**	**How is this represented in the literature – does it Agree Disagree Add another dimension**	**How does this relate to wider health and social care agendas re: Policy Practice Education**
5 Jamaicans don't do that	This theme was captured by the strong responses evoked when probe about placing their family member in a care facility (nursing home)	Unconscionable "What would that say about us as Black people?" "…'let down my parents" "I could never put my mother in a nursing home" "Would not trust them not to ill-treat my parent" "Over-reliant on medication" "Only if/when physical care needs overwhelming"	**2** **3**	Gottleib & Johnson (2000) Obvious example of proactive coping is effort made to prepare for relatives' eventual placement in a long term care facility Findings disagree Cloutterbuck & Mahoney (2003) Expectation that families should and would provide care Findings agree	This relates to policy and practice Dilworth-Anderson et al. (2002) Families providing support to an elder living with dementia can be viewed as a wider process of cultural normalisation in which the norms attitudes and practices that act as unique identifiers of a community are passed across generations

				McKenzie (2006) Lawrence et al. (2008) Parveen et al. (2014) Value held by families to able to care for a relative living with dementia Findings agree	
Theme	**What is this theme about?**	**Examples from data that illustrate how participants spoke about this**	**Which research objective does this address?**	**How is this represented in the literature – does it Agree Disagree Add another dimension**	**How does this relate to wider health and social care agendas re: Policy Practice Education**
6 The church needs to do more	This theme was captured in narratives that suggested a more prominent role was needed from the church There was a notion that dementia was hitting the Jamaican community in way no one saw coming, so the response would have to be as a community	"'Disappointed with church support" "Church does not appear interested" " Church should be offering financial help after years of tithes and offerings" "… need to harness that energy and influence to educate and advise"	**1** **3**	Mukadam et al. (2011) Regan et al. (2013) BAME communities are under presenting in specialist services and more likely to fall back on and draw on services more familiar such as faith institutions Finding agree Cloutterbuck & Mahoney (2003) Argue that religion not important for caregivers Findings disagree Taylor et al. (2005) Bashi (2007) Chatters et al. (2008) Black Caribbean churches have long standing tradition providing social and psychological support helping to maintain ethnic identity and mediate the broader racial, social, and cultural environments Findings agree Blank et al. (2002) Black churches shown to be informal service provider and used as an entry point for services	This relates to policy and practice Jutlla (2013) Seabrooke & Milne (2009) Moriarty et al. (2011) While this may be associated with a lack of knowledge about dementia or available services It is important to frame this pattern of use and non use within wider context of culture, race and ethnicity Zunzunegui et al... (2003) Government in England and Jamaica be encouraged to assist churches provide more opportunities for social integration of elders though day centres and seniors clubs which would facilitate support elders and their caregivers

				Holt & McClure (2006) Nooney & Woodrum (2002) Positive effect of church attendance and having a church community Findings agree Haley et al. (2004) Waliser et al. (2001) Farran et al. (2003) Highlight role that religiosity plays in supporting caregivers Findings agree Levine (2003) Payer as part of toolkit for coping Findings agree Putnam (2000) social engagement eroding Findings add another dimension – Jamaican communities are instead evolving – sharing information and getting support through church community rather than though health or social care agencies and Alzheimer's Jamaica is a hub for information not just in Jamaica but also in England	

Table 4:2 Summary of findings mapped against research aim and objectives